A LONGITUDINAL OBSERVATIONAL STUDY OF AGGRESSIVE BEHAVIOUR IN ADULTS WITH INTELLECTUAL DISABILITIES

by

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ABSTRACT

Background:

Aggressive behaviour exhibited by adults with intellectual disabilities (ID) can negatively affect the person and those around them.

Aims:

To longitudinally investigate the topography and trajectory of aggressive behaviour and to identify cross-sectional and prospective risk factors including personal characteristics, co-morbid conditions and contextual factors in a clinical cohort.

Methods:

Structured interviews with carers of 100 adults with ID who exhibit aggressive behaviour were conducted three times over 12 months, at six-month intervals. Questionnaires and standardised assessment scales were administered at each time point to assess aggressive behaviour, including triggers, other problem behaviour, quality of life, carer's outcomes, mental health problems, physical health conditions and demographic variables.

Results:

Aggressive behaviour was long-standing, however, behaviour improved with 43% demonstrating a reliable improvement. A model of severity of aggressive behaviour accounted for 50-54% of the variance at follow-up. Those with more severe ID were over 3 times more likely to exhibit self-injurious behaviour and females were over 5 times more likely to exhibit verbal aggression. Carers implicated a wide range of contextual variables as triggers for aggressive behaviour.

Conclusions:

A clinical profile of topography of aggressive behaviour, including risk factor profile among adults with ID may guide interventions and inform service provision.

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ABBREVIATIONS

ABC	Aberrant Behaviour Checklist
ABC-I	Aberrant Behaviour Checklist Community – Irritability, Agitation and Crying Subscale
ADHD	Attention deficit-hyperactivity disorder
ASD	Autism spectrum disorder
CI	Confidence interval
CLDT	Community Learning Disability Team
ICC	Intra-class correlation coefficient
ID	Intellectual disability
IQR	Inter-quartile range
MOAS	Modified Overt Aggression Scale
OCD	Obsessive compulsive disorder
PAS-ADD	Mini Psychiatric Assessment Scale for Adults with Developmental Disabilities
QABF	Questions About Behavioural Function
SIB	Self-injurious behaviour
T1	Interview 1 (baseline)
T2	Interview 2 (six month follow-up)
T3	Interview 3 (12 month follow-up)

CHAPTER 1: BACKGROUND, INTRODUCTION, AIMS AND RESEARCH QUESTIONS

This chapter presents a conceptual review of the field of intellectual disability (ID) research to establish the context for, and issues to be covered in, the thesis. Salient papers have been selected to be representative of the field and to build the aims for the thesis by identifying knowledge gaps and developing hypotheses. More detailed reviews of relevant literature can be found within subsequent chapters.

Definitions and Prevalence of Intellectual Disabilities (ID)

Intellectual disability (ID) is defined as 'arrested or incomplete development of the mind, which is usually characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities... [It] can occur with or without any other mental or physical condition' (Ch. V, World Health Organisation, WHO, 2010). The core criteria for ID therefore comprise impairments in both intellectual and adaptive/social functioning with age of onset before adulthood (British Psychological Society, BPS, 2000). Assessment of intellectual functioning usually utilises standardised psychometric testing, often intelligence tests, to estimate intelligence quotient (IQ) with a common cut-off for ID being IQ below 70 (WHO, 2010). The BPS (2000) defines an impairment in adaptive/social functioning as 'the individual requires significant assistance to provide for his/her own survival (eating and drinking needs and to keep himself/herself clean, warm and clothed) and/or with his/her social/community adaptation (e.g. social problem solving, and social reasoning)' (p. 5). The WHO (2010) classifies degree of intellectual impairment into four categories, from mild to profound. Mild ID is defined as IQ between 50 and 69, with an approximate corresponding mental age in adults of nine to 11 years. Many adults with mild ID live independently, work and maintain relationships. Conversely, those with severe or profound ID (IQ 34 or below) are likely to require continuous support with many aspects of daily living and have difficulties with self-care, continence, mobility and communication.

ID is currently the preferred term amongst the international scientific community to describe this condition and is therefore used throughout this thesis (for example, the International Association for the Scientific Study of Intellectual Disabilities; IASSID). However, health and social care systems in the United Kingdom tend to use the term ‘learning disability’ (Emerson & Einfeld, 2011; BPS, 2000). Furthermore, the term ‘mental retardation’ is still used internationally, as in the *International Statistical Classification of Diseases and Related Health Problems 10th Revision* (ICD-10, WHO, 2010) but its use is currently being phased out. For example, the recently published *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-V; American Psychiatric Association, APA, 2013) replaces ‘mental retardation’ with ‘intellectual disability/intellectual and developmental disorder (IDD)’. Similarly, a WHO working group on the revision of ICD-10 has suggested the term, ‘intellectual developmental disorders’ (Salvador-Carulla et al, 2011).

Emerson and Hatton (2004) estimate the administrative prevalence of ID (people who are known to ID services) in England to be 0.46% of the general population. However, this estimate overlooks those who are not known to services; they therefore estimated the true prevalence of ID to be 2.2% of the general adult population of England. More recently, it has been estimated that in 2010 there were 900,000 adults with ID living in England, of whom only 191,000 (21%) were known to services (Emerson et al, 2011a). A recent meta-analysis estimates the world-wide prevalence of ID to be 1.04% (Maulik et al, 2010).

Definitions and Prevalence of Aggressive Behaviour

Adults with ID commonly have significant health and social care needs relating to mobility, continence or behaviour (Emerson & Hatton, 2004). Aggressive behaviour often requires input from specialist services (Lundqvist, 2013) and it has been estimated that around 15% of people with ID require clinical intervention for aggressive behaviour (Sigafoos et al, 2003). Aggressive behaviour can include verbal aggression, physical aggression to others, property destruction and self-injurious behaviour (SIB; physical aggression towards the self). Some consider aggressive behaviour to be a sub-type of challenging behaviour. However, others use the term 'challenging behaviour' as synonymous with aggressive behaviour or consider challenging behaviour to be a more severe form of problem behaviour, sometimes encompassing the forms of aggressive behaviour outlined previously, with and without verbal aggression. This discrepancy in terminology, often with a lack of clear description, coupled with methodological variation between studies creates difficulties in estimating the prevalence of such behaviours and in consistently identifying risk factors and associations (Benson & Brooks, 2008).

Emerson and Einfeld (2011) suggest that 'challenging behaviour' has been used to replace other terms such as maladaptive, abnormal or aberrant behaviour. They clarify that this is now the preferred term, as some behaviours encompassed by this term may be orderly and functional given the circumstances of the individual with the focus shifting to services and their challenge to meet the needs of the person and to the social context in which such behaviours function. Emerson (1995) defined challenging behaviour as 'culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities'. Emerson and Einfeld (2011) emphasise that challenging behaviours 'involve significant risks to people's physical well-being or act to markedly reduce access to community settings' (p. 4). In this way, challenging behaviour refers to more severe behaviour. Whilst aggressive behaviours represent the core of challenging behaviour (Tsiouris et al, 2011) using this definition would place assumptions on the severity of behaviours and could include a broader range of behaviours such as pica, disruptive and oppositional behaviours, hyperactivity or social withdrawal and may exclude non-physical (verbal) aggression (Hasting & Brown, 2013).

Due to discrepancies in the use of the term 'challenging behaviour', some professional organisations prefer to use other terms. The Royal College of Psychiatrists (RCPsych, 2001) uses the term 'problem behaviours' and stipulates that there are no implied assumptions as to the long-term prognosis or aetiology of the behaviour. Problem behaviour incorporates several categories of behaviour, including, among others, the four types of aggressive behaviour, as well as sexually inappropriate behaviour, demanding behaviour and wandering. The term 'problem behaviour' was also favoured in a national (Unwin & Deb, 2010) and international guide for psychotropic use (Deb et al, 2009), and the WHO revision of ICD-10 working group (Salvador-Carulla et al., 2011).

There have been many attempts to determine the occurrence of problem, aggressive and challenging behaviours in people with ID; however, these rely on accurate diagnostic strategies that have been subject to some criticism, often relying on others' perceptions and report (Deb et al, 2001a). Similarly, prevalence rates vary due to different populations (for example, in ages and location of study), time-scales and forms of prevalence (for example, point prevalence, life-time occurrence or time-limited incidence) under study (Allen, 2000). Epidemiological studies report rates of around 60% for problem behaviour (e.g. Lundqvist, 2013; Deb et al, 2001a; Smith et al, 1996; Jacobsen & Janicki, 1985; Koller et al, 1983). Rates of challenging behaviour tend to be lower with point prevalence rates of around 10-15% (Lundqvist, 2013; Lowe et al, 2007a; McClintock et al, 2003; Deb et al, 2001a; Emerson et al, 2001a) supporting the notion that challenging behaviour refers to a more severe subset of problem behaviour. Prevalence of aggressive behaviours tends to fall somewhere in between, however, higher and lower prevalence figures have also been reported. Crocker and colleagues (2006) report in their literature review that prevalence rates can vary from 2%-60%. Studies of all four types of aggressive behaviour tend to report verbal aggression as being the most common (see Table 1 and see Cooper et al, 2009a; 2009b for a detailed review of prevalence). Often, adults with ID exhibit multiple forms of aggressive behaviour and other types of problem behaviour (Oliver et al, 2012; Lowe et al, 2007a; Cooper et al 2009a; Cooper et al, 2009b; Harris, 1993) and the sub-types of aggressive behaviour demonstrate significant associations with each other in terms of severity (Taylor et al, 2011; Lowe et al, 2007a; Crocker et al, 2006). However, there is little research that has explored the topography of aggressive behaviour in adults with ID in detail, and the field remains dominated by retrospective research lacking detailed descriptions of aggressive behaviours in specific settings (Tenneij & Koot, 2008).

For clarity, the term ‘aggressive behaviour’ is used throughout to refer to a specific set of behaviours that could be of any severity and aetiology. Aggressive behaviour is defined as ‘any verbal, non-verbal, or physical behaviour that was threatening (to self, others or property), or physical behaviour that actually did harm (to self, others, or property)’ (Morrison, 1990 cited in Tenneij & Koot, 2008, p. 116). This definition corresponds with a commonly used measure to assess aggressive behaviour (the Modified Overt Aggression Scale, MOAS, Ratey & Gutheil, 1991) and with existing literature in the field. Whilst prevalence figures for aggressive behaviour vary, it has been demonstrated that such behaviour is common among adults with ID (Hemmings et al, 2013; Benson & Brooks, 2008) (see Table 1).

Table 1: Prevalence and incidence of aggressive behaviour (%)

Author Year	Aggressive behaviour	Verbal aggression	Property destruction	Physical aggression to others	SIB	Sexual aggression
Tsiouris et al 2011	83	72	46	58	40	-
Cooper et al 2009a; 2009b	-	9.8			4.9	-
Jones et al 2008	22.5	7.5	3.0	6.3	4.9	-
Myrbakk & von Tetzchner 2008	65	-	-	-	-	-
Crocker et al 2006	51.8	37.6	24.0	24.4	24.4	9.8
Tyrer et al 2006	-	-	-	14	-	-
Deb et al 2001a	-	28.7[a]	11.9	22.8	23.8	-
Emerson et al 2001a	-	-	4-5	7.0	3.4	-
Smith et al 1996	-	22[a]	17.2	21.6	17.4	-
Sigafoos et al 1994	11	-	-	-	-	-
Bouras & Drummond 1992	-	-	27	33	13	-
Jacobsen 1982	-	5.9	4.3	10.9	-	-

[a] Screaming/shouting

The Impact of Aggressive Behaviour

Despite aggressive behaviours receiving a considerable amount of research attention, such behaviours continue to be a major concern for families, carers, clinicians and other professionals (Emerson & Einfeld, 2011) acting as a major barrier to social integration/inclusion and limiting access to certain residential settings, education, occupational opportunities or social acceptability (Bigby, 2012; Crocker et al, 2006; Harris, 1993; Gardner & Moffat, 1990). Those who exhibit aggressive behaviours are perceived to be less satisfied with their life situation than those without and tend to have poorer quality of life (Murphy, 2009; Myrbakk & von Tetzchner, 2008a) with a reduction in behaviour being linked with improved quality of life (Hatton et al, 2004; Perry & Felce, 2003). Presence of these behaviours inevitably increases the risk of personal injury for the person and those around them. Furthermore, it is has been reported that aggressive behaviour predicts admission to psychiatric inpatient units (Cowley et al, 2005), is the most common reason for referral to mental health services or specialist behavioural support teams (Tenneij et al, 2009; Maguire & Piersel, 1992; Szymanski et al, 1991; Hill & Bruininks, 1984), is related to use of psychotropic medication (Lundqvist, 2013; Taylor et al, 2011), is associated with out of area residential placements (Allen et al, 2007; Jaydeokar & Piachaud, 2004), placement breakdowns (Emerson & Robertson, 2008), use of restraint and restrictive practices (Merineau-Cote & Morin, 2013; Scheirs et al, 2012; Sturmey, 2009; Sturmey et al, 2005; Emerson et al, 2000), and higher cost of service provision (Hassiotis et al, 2008; Knapp et al, 2005; Hallam et al, 2002). Recently, screaming and shouting (verbal aggression) independently predicted use of physical restraint in group homes over and above a wide range of other variables (Lundström et al, 2011). Frequency of aggressive behaviour has been reported to be the best single predictor of restraint-related injury, with one in three emergency personal restraints resulting in personal injury (Tilli & Spreat, 2009).

Aggressive behaviour also impacts on paid carers, informal carers, and family members, including siblings, with aggressive behaviours a common source of stress leading to negative emotions (Cudré-Mauroux, 2011; Lambrecht et al, 2009; Benderix & Sivberg, 2007; Lecavalier et al, 2006; Hastings, 2005; Bell & Espie, 2002) whilst staff attribution of control may play a mediating role in risk of placement breakdown (Rose et al, 2013a). Aggressive behaviour is perceived to have a negative impact on families by mothers and is a significant source of family carer burden (Hartley et al, 2012; Maes et al, 2003; McIntyre et al, 2002; Heller et al, 1997a; Hodapp et al, 1992). Recently, 92% of staff in community homes reported that they have had some exposure to aggressive behaviour within the last six months, with around 20% experiencing physical aggression resulting in personal injury

(Hensel et al, 2012). Paid carers, working in community group homes with residents who exhibit aggressive behaviour, report lower job satisfaction and more anxiety compared to similar workers in homes without such residents (Jenkins et al, 1997) and a significant relationship between aggressive behaviours and staff burnout has been reported (Vassos & Nankervis, 2012; Mills and Rose, 2011). In addition, 42% of all carers of adults who exhibit physical aggression towards others reported that they felt unable to cope with the behaviour, rising to 58% for family carers of those known to services (Tyrer et al, 2006) with fear of assault relating to emotional exhaustion (Rose et al, 2013a).

Natural History of Aggressive Behaviour

Aggressive behaviour is commonly considered as a chronic and enduring condition, with aggression during childhood a major predictor of aggression later in life (May, 2011; Emerson et al, 2001b). Few studies have investigated the age at which such behaviour tends to first emerge, however, available studies suggest that behaviours often appear in childhood (Murphy et al, 1999; 1993). Cross-sectional research reports that prevalence tends to increase with age, peaking in adolescence/early adulthood and then declining from around 30-35 years (Tomic et al, 2012; Tyrer et al, 2006; Deb et al, 2001a; Borthwick-Duffy, 1994; Sigafoos et al, 1994). A recent review concluded that most studies tend to show a relationship of significant increases in prevalence from childhood until mid-adulthood with some limited evidence of a curvilinear relationship of decreasing prevalence from around age 45-50 years (Davies & Oliver, 2013). However, the authors report that there are problems in drawing conclusions from cross-sectional prevalence studies, such as differential mortality rates and that many researchers have failed to identify a relationship between aggressive behaviours and age.

The pattern reported in cross-sectional research suggests that remission with age occurs for some individuals. Conversely, existing longitudinal research suggests such behaviours tend to be chronic with persistence rates of 50% to 90% reported with rates varying according to type of behaviour and time period studied (Totsika et al, 2008; Thompson & Reid, 2002; Emerson et al, 2001b; Kiernan & Alborz, 1996). Cooper and colleagues (2009a; 2009b) comment that whilst previous literature has considered aggressive behaviour to be an enduring condition, there is relatively little published research to corroborate this assertion and report two-year remission rates of 29% to 38%. However, they acknowledge that the remission rates might have been the result of participants being offered intervention from psychiatrists and psychologists as part of the study. The limited longitudinal literature tends to examine persistence of aggressive behaviour rather than investigating fluctuations in severity, with few studies examining the course of aggressive behaviour over time. It is possible that whilst prevalence may remain for the majority, fluctuations in severity and topography of aggressive behaviour may occur. For example, Thompson and Reid (2002) concluded from their longitudinal study of people with severe and profound ID, that a high number of behavioural problems persisted over the 26-year period of the study, however, whilst the number of behavioural symptoms remained relatively stable, the severity lessened.

Very little recent research has studied the natural history and trajectory of aggressive behaviour in adults with ID (Horowitz et al, 2011). The purported chronicity may indicate that current interventions have limited success, however, longitudinal research that investigates the trajectory of aggressive behaviour of those who are in contact with services is required. Furthermore, the author is not aware of existing research that has also considered the trajectory of related variables over time. Research has shown that aggressive behaviour has a negative impact on the quality of life of the person themselves and those around them (see previous discussion), however, the relationships between chronicity of aggressive behaviour and other outcomes, such as quality of life and outcomes for carers, have not been studied.

Aetiology of Aggressive Behaviour

Historically, explanations of the development and maintenance of aggressive behaviour of people with ID largely fell into two schools, namely, the biological model (including medical and physical factors) and the behavioural model (focussing on learned behaviour and the environment) (Hemmings et al, 2013; Emerson & Einfeld, 2011). More recently, clinical guidance on assessing aggressive behaviour of adults with ID has highlighted the importance of a holistic, multidimensional approach including assessment of behavioural, medical, psychiatric and social factors (Unwin & Deb, 2010). It is likely that a combination of biological and environmental factors is involved and most experts now agree that aggressive behaviour is multi-determined (Benson & Brooks, 2008). However, direct causal mechanisms have not yet been identified (May, 2011; Janssen et al, 2002) and Emerson & Einfeld (2011) comment that it is impossible to present a single model that could account for complexities of pathways to the development and maintenance of aggressive behaviour.

Firmly rooted in the biological model of aggressive behaviour is the notion of genetic syndromes linked to ID which produce distinct behavioural phenotypes through developmental brain damage. For example, Cri du Chat, Cornelia de Lange, Angelman, Fragile X, Prader-Willi, Lowe, Smith Magenis, Lesch Nyhan, Rett and Brachmann de-Lange syndromes are known to carry a higher risk for certain types of behaviours such as physical aggression and SIB (Arron et al, 2011; Deb, 1998; Deb, 1997). Conversely, research has demonstrated that those with Down syndrome are less likely to exhibit physically aggressive behaviour (e.g. Tyrer et al, 2006; Esbensen et al; 2008; Collacott et al, 1998a). Further investigations of the determinants of aggressive behaviour have attempted to isolate specific genetic conditions and have reported that monoamine oxidase was associated with aggressive behaviours in adults with ID, suggesting that a common variant in the monoamine oxidase gene may be responsible (May et al, 2009). May and colleagues (2010) also hypothesised that serotonin transporter polymorphisms in adult males with ID may relate to aggressive behaviour, however, they conclude that the relationships between genes and behaviours are likely to be complex, with multiple genes and environmental interactions involved.

Along with the purported association between aggressive behaviour and more severe degree of intellectual impairment (e.g. Crocker et al, 2006; Tyrer et al, 2006; Borthwick-Duffy, 1994), researchers have implicated an organic cause in the form of neurological damage in the absence of a specified genetic condition (Davison & Neale, 1974). Allen (2000) suggests that such damage may be linked to neuro-cognitive sequelae, such as poor impulse control, impaired memory and reduced attention span, all features of ID that may predispose aggressive behaviour. Such factors are also related to psychiatric illnesses with a significant biological origin (for example, depression or psychosis). It has been suggested that aggressive behaviours may be the direct manifestation of psychiatric disorders, considered as behavioural equivalents, especially in those with severe or profound ID (Clarke & Gomez, 1999; Marston et al, 1997). However, others have challenged this position and the relationship continues to be questioned, particularly in relation to specific psychiatric disorders such as depression (Sturmey et al, 2010b; Allen & Davies, 2007; Tsiouris et al, 2003a; Deb et al, 2001b; Matson & Mayville, 2001; Tsiouris, 2001). Others have suggested that psychiatric illness may provide a motivational basis for aggressive behaviour (Holden & Gitlesen, 2008; Carr et al, 1996; Lowry & Sovner, 1992).

Further biological explanations include issues around pain, which is often under-recognised in people with ID, largely due to communication difficulties and diagnostic overshadowing (O’Hara, 2010; Symons et al, 2008). This, along with increased prevalence of health conditions (de Winter et al, 2011; O’Hara et al, 2010; van Schrojenstein Lantman-de Valk et al, 1997), may indicate that aggressive behaviour is the manifestation of an uncomfortable/aberrant internal state, with pain reducing the capacity for adaptive behaviour (Breau et al, 2007). Indeed, chronic pain and expressions of behavioural signs of pain have been linked to increased levels of aggressive behaviour in adults with ID (Walsh et al, 2011; Symons et al, 2009). Furthermore, some authors have suggested that pain regulation may be disturbed in some people with ID (Emerson & Einfeld, 2011). For example, Autism Spectrum Disorder (ASD), which has a high co-morbidity with ID (Matson & Shoemaker, 2009), has been associated with sensory processing abnormalities, including hypersensitivity and hyposensitivity to pain (Nader et al, 2004; Gilberg, 1995). Most commonly, ASD has been associated with hyposensitivity to pain, purported to be through a hyperfunctioning endogenous opioid system (Nader et al, 2004; Gilberg, 1995). SIB has also been linked to dysregulation of biological systems in numerous animal and human studies, especially a dysregulated opioid system (Furniss & Biswas, 2012; Sandman & Touchette, 2002; Sandman & Hetrick, 1995). Indeed, SIB is considered by some to be most likely biologically motivated (Sandman & Touchette, 2002). Behaviourists consider aggressive behaviour to arise from such biological or internal factors and be subsequently maintained by automatic or perceptual reinforcement, whereby behaviours serve to moderate the experience of pain or levels of over arousal (Emerson & Einfeld, 2011). Various other predisposing biological states have also been cited including illness, allergies, fatigue, sleep problems, hormonal changes and diet and food deprivation (Emerson & Einfeld, 2011).

Behavioural models of aggressive behaviour focus on behavioural determinants; the move towards these models implicated environmental factors rather than the previously held assertion that behaviour was the external manifestation of an internal pathology (Emerson & Einfeld, 2011). The predominant approach in the field is applied behaviour analysis which views aggressive behaviours as examples of operant behaviour whereby behaviours are shaped and maintained by their environmental consequences (Emerson & Einfeld, 2011; Asmus et al, 2004; Emerson & Bromley, 1995). Research has implicated operant learning in increasing the severity and persistence of aggressive behaviours (Oliver et al, 2005; Oliver, 1995; Iwata et al, 1994a). Behaviours are shaped through interactions with both the physical and social world, as May (2011) describes:

> “Aggression can be maintained by social positive reinforcement contingencies if the behaviour is emitted to access people, places, or things, ... social negative reinforcement contingencies if the behaviour is emitted to avoid or escape people, places, or things... [or] non-social reinforcement [which] can be positive if the behaviour produces a rewarding consequence, or negative if the behaviour alleviates pain or aversive sensory stimulation.” (p. 2215)

Historically, research has focussed on consequences as determinants of behaviour, with little attention given to the influence of antecedent events (Smith & Iwata, 1997); however, growing attention was given to the role of antecedent events in the development of the antecedent-behaviour-consequence (A-B-C) framework (Carr et al, 1994). In interpreting the consequence as providing reinforcement, behaviourists suggested that the behaviour serves a function for the individual (Carr et al, 1990; Mace, 1994). Functional analysis explores the relationships between situational/contextual variables and the behaviour to locate a motivation or function for the behaviour and to provide explanations for the maintenance and development of the behaviour (e.g. May, 2011). Functions for aggressive behaviour commonly include obtaining tangible items, obtaining sensory reinforcement, getting attention, avoiding or escaping aversive situations or social situations, and non-social, such as self-stimulatory behaviour (Matson et al, 2011; Carr, 1994). This is consistent with models provided by the generic aggression literature, namely the ‘social learning’ and ‘aversive stimulation’ models (Breakwell, 1989).

The development of the functional approach is considered as an important advancement in the field (Matson et al, 2012a; Emerson & Einfeld, 2011) leading to the development of successful methods for assessment and intervention (O’Reilly et al, 2012; Hastings & Brown, 2000; Matson et al, 1999; Pelios et al, 1999). Commonly, positive behaviour support, derived from functional (consequence-based) and contextual (antecedent-based) assessment, is implemented which aims to apply behavioural principles in the community to reduce problem behaviours and build appropriate behaviours using environmental modification and training (Carr et al, 1999; see Dunlap & Carr, 2007 for a review). More specifically, positive behaviour support comprises four categories of intervention: 'altering the environment before problem behaviour occurs via the implementation of strategies such as stimulus-based intervention, expansion of choice, and manipulation of setting events; teaching appropriate behaviours through self-management and functional communication training; ensuring that appropriate behaviours are more strongly reinforced than challenging behaviours; and reacting to behaviour so as to optimise safety and dignity, while minimising inadvertent reinforcement of behaviour' (McClean & Grey, 2012, p. 221).

Current behavioural models focus on maintaining processes, such as reinforcement. Implicit within these models is the notion that such basic learning processes are responsible for the development of aggressive behaviours (Hasting & Brown, 2000). For example, Gardner and Moffat (1990) combined aspects of the biological and behavioural models for aggressive behaviour to propose the 'biopsychosocial' model. This predominantly behavioural model implicates personal or environmental factors that may 'set the scene' for aggression, highlighting the learning processes by the individual through which the behaviours may be strengthened and maintained or weakened and reduced (Allen, 2000). The role of carers in shaping behaviours through habituation has been implicated in the development of aggressive behaviour (Oliver, 1993; Guess & Carr, 1991). Carers may 'get used to' the aggressive behaviour displayed by the individual, only responding to more and more intense or complex forms over time, thus differentially reinforcing aspects of the behaviour already exhibited by the individual (Emerson & Einfeld, 2011). Equally, carers often seek to avoid aggressive behaviour, thus avoiding interactions with those whose aggressive behaviour is maintained by negative social reinforcement and increasing interaction with those whose behaviour is maintained by positive social reinforcement, providing further reinforcement of the behaviours

(Carr et al, 1991). Cycles of negative reinforcement have been termed 'benevolent enslavement' whereby the behaviours themselves negatively reinforce the behaviour of the carer who seeks to escape or avoid the aggressive behaviour, resulting in a 'negative reinforcement trap' (Taylor & Carr, 1993; Carr et al, 1991).

Despite the existing theoretical literature, the development of aggressive behaviour is still poorly understood (Davies & Oliver, 2013; Hasting & Brown, 2000). Some models of the development of SIB have been provided, although little attention has been paid to the development of other types of aggressive behaviour (Davies & Oliver, 2013; Hastings & Brown, 2000). For example, Guess and Carr's (1991) three-stage developmental model of SIB suggests that this emerges from repetitive/stereotyped behaviours that are first displayed in the course of normal human development and are regulated internally (via biological processes with a homeostatic function to regulate degree of stimulation) with later evolution into SIB, produced to modulate levels of arousal, strengthened by reinforcement through the physical environment that precedes control via the social environment (Hastings & Brown, 2000). The operant model of the development of SIB has received some compelling support in the literature, especially in relation to the strengthening of SIB, however, studies do not support the notion that 'social reinforcement processes are responsible for shaping stereotypy into SIB' (Furniss & Biswas, 2012). It is therefore possible that SIB and outwardly-directed aggressive behaviour have different aetiologies.

Demographic/Personal Risk Factors and Associations with Aggressive Behaviour

Epidemiological research has sought to identify factors, both within the person and, less commonly, in the environment, that are associated with aggressive behaviour. Identifying such correlates aids the understanding of the processes involved in a person displaying aggressive behaviour, as well as helping to develop effective management strategies and inform service provision (Felce & Kerr, 2013; Cooper et al, 2009a; Cooper et al, 2009b; McClintock et al, 2003). Studies have attempted to establish risk factors associated with prevalence of aggressive behaviour, fewer studies have sought to examine the associations with severity, frequency and type of aggressive behaviour and very few have sought to study aggressive behaviour and its correlates prospectively (Tenneij & Koot, 2008). Most commonly, personal, constant or relatively stable, internal, demographic risk factors are studied (Hemmings et al, 2013; see Cooper et al, 2009a; 2009b for a detailed review) with frequently cited risk markers including degree of intellectual impairment, gender, age, communication abilities, physical disabilities, sensory impairments, presence of ASD, and residential setting; less frequently reported risk markers include epilepsy, psychiatric diagnoses, and concomitant problem behaviours (McClintock et al, 2003). Crocker and colleagues (2006) comment that there remains a paucity of literature on factors associated with aggression, especially in those with mild or moderate ID. Furthermore, recent systematic reviews of risk factors for SIB and physical conditions associated with aggressive behaviour have highlighted contradictory results and poor quality studies (Furniss & Biswas, 2012; de Winter et al, 2011).

Of the research that does exist, varying conclusions have been drawn, for example, studies have demonstrated that prevalence of each type of aggressive behaviour positively correlates with increasing degree of intellectual impairment (e.g. Crocker et al, 2006; Tyrer et al, 2006; Deb et al, 2001a: for SIB; Borthwick-Duffy, 1994). However, other studies have found no effect (Drieschner et al, 2013; Deb et al, 2001a: for physical aggression; Aman et al, 1995) and some have reported the opposite effect (Emerson et al, 2001a, for physical aggression and in relation to self-care skills). Crocker and colleagues (2006) found that adults with mild or moderate ID were more likely to display verbally aggressive behaviour, whereas adults with severe or profound ID were more likely to exhibit physical aggression, indicating that the relationships may differ for different types of behaviour which may explain the varying existing results (see Chapter 5 for a more detailed introduction to the literature). Currently, aggressive behaviour is thought to be associated with more severe ID, the male gender (most notably outwardly-directed aggression), younger adults and adolescents, syndromes such as ASD and restricted communication skills (Emerson, 2001).

A meta-analysis sought to evaluate various putative risk factors for challenging behaviour, including aggressive behaviours and stereotypical behaviours of people with ID by synthesising cohort and prevalence studies (McClintock et al, 2003). McClintock and colleagues (2003) only examined a limited pool of risk markers as sufficient data were available to calculate odds ratios. However, they observed that other factors were frequently cited in the literature including mobility, age and residential setting, but there were insufficient data to be included in the analysis. The authors report several significant risk factors: severe-profound ID was strongly associated with SIB, however, there was no association with outwardly-directed aggression; outwardly-directed aggression was associated with the male gender, there was no such gender association for SIB; presence of ASD was associated with presence of SIB, property destruction and outwardly-directed aggression; and deficits in expressive and receptive communication were associated with SIB but not with outwardly-directed aggression.

The results of this meta-analysis should be taken with caution, as only a small number of studies were included in the analyses; typically 2-6 studies contributed to the analysis for each factor. Furthermore, the results of heterogeneity analyses suggest that results varied widely across studies with significant heterogeneity between studies for most analyses. Differences between studies may be due to differences in operational definitions, sampling strategies and strategies for case selection (Emerson & Einfeld, 2011). In addition, the authors acknowledge that many of the risk factors identified in the meta-analysis overlap and inter-relate to some extent, for example, deficits in expressive communication are related to autism and autism is more common in those with more severe ID, as are communication problems (Matson et al, 2013). The authors speculate that a risk marker profile for aggressive behaviour exists but suggest that further research is required which examines the relative association of variables. Furthermore, they highlight that other risk markers may exist but they were not entered into the meta-analysis due to lack of available data.

Whilst there is a pool of research literature examining risk factors and associations for aggressive behaviour of adults with ID, implicating some personal characteristics in the aetiology of aggressive behaviour (Arron et al, 2011), the relationships are far from clear. Much research seeks to identify cross-sectional individual risk factors with presence of aggressive behaviour, which does not account for the overlap between factors or associations with severity. Further research is needed to examine these connections with prospective data collection, large sample sizes and which addresses chronicity to establish a clear risk factor profile. Furthermore, it may be important to consider sub-types of aggressive behaviour separately as well as severity of aggression as a continuum (see Darrow et al, 2011 for a review of issues associated with the identification of risk factors).

Environmental/Contextual Risk Factors for Aggressive Behaviour

Recently, ID is understood with an ecological perspective that emphasises the interactions between a person and their environment (Claes et al, 2012). The environment has also been implicated in the aetiology of aggressive behaviour through social learning (Arron et al, 2011). Allen (2000) comments that ‘physical or psychiatric conditions alone rarely account for aggressive behaviour, and it is likely to be a complex combination of stimuli that includes environmental pollutants’. Various dynamic environmental factors have been implicated including heat, noise, crowding, inexperienced staff and lack of structured activity (Blumreich & Lewis 1993; Harris & Rice, 1992). In this way, environmental factors may include both physical and social elements. The ‘most commonly studied of these factors have been via functional assessment methods’ (Matson et al, 2011). In a literature review, Matson and colleagues (2011) report that among 173 papers utilising functional assessment of challenging behaviour, in 97% of cases, at least one function for the behaviour could be identified. However, the authors comment that this figure could be inflated due to reporting bias.

Existing literature indicates high levels of contextual control through positive and negative reinforcement suggesting that most aggressive behaviours are socially-motivated (e.g. Applegate et al, 1999; Iwata et al, 1994a; Carr & Durrand, 1985; Iwata et al, 1982) and thus provide social consequences relating to attention or escape (Matson et al, 2011). Emerson and Einfeld (2011) summarise from existing literature that around 71% of challenging behaviours of people with predominantly severe ID may be maintained by some form of social reinforcement with negative reinforcement (for example, escape; 46%) more common than positive (for example, attention; 37%), in this way, much aggressive behaviour is considered to serve a communicative function (Matson et al, 2011; Hastings & Brown, 2000). Researchers have suggested that people with ID and subsequent limited communication skills 'rely primarily on expressive behaviour to communicate their wants and needs...these limited skills can lead to communication in the form of...behaviour such as aggression' (Singh et al, 2009). Indeed, lower levels of language skill have been associated with aggressive behaviours (Bott et al, 1997; Chamberlain et al, 1993). Interventions have therefore been developed to improve communication skills and thus reduce aggressive behaviour, such as functional communication training which has been shown to be effective (Reeve & Carr, 2000; Carr & Durrand, 1985). As carers are key features of the environment, and, acting as mediators, are responsible for providing reinforcement and receiving communicative attempts by the individual, interventions with carers may also be valuable (Allen, 1999). Behavioural training for carers has been shown to improve knowledge, attitudes and emotions and reduce aggressive behaviour of the person cared for (Hutchinson et al, 2012; McClean & Grey, 2012; Costello et al, 2007; Dowey et al, 2007; Grey & McClean, 2007; McClean, 2007; McClean et al, 2005; Hatton et al, 2004; Hastings and Brown, 2000).

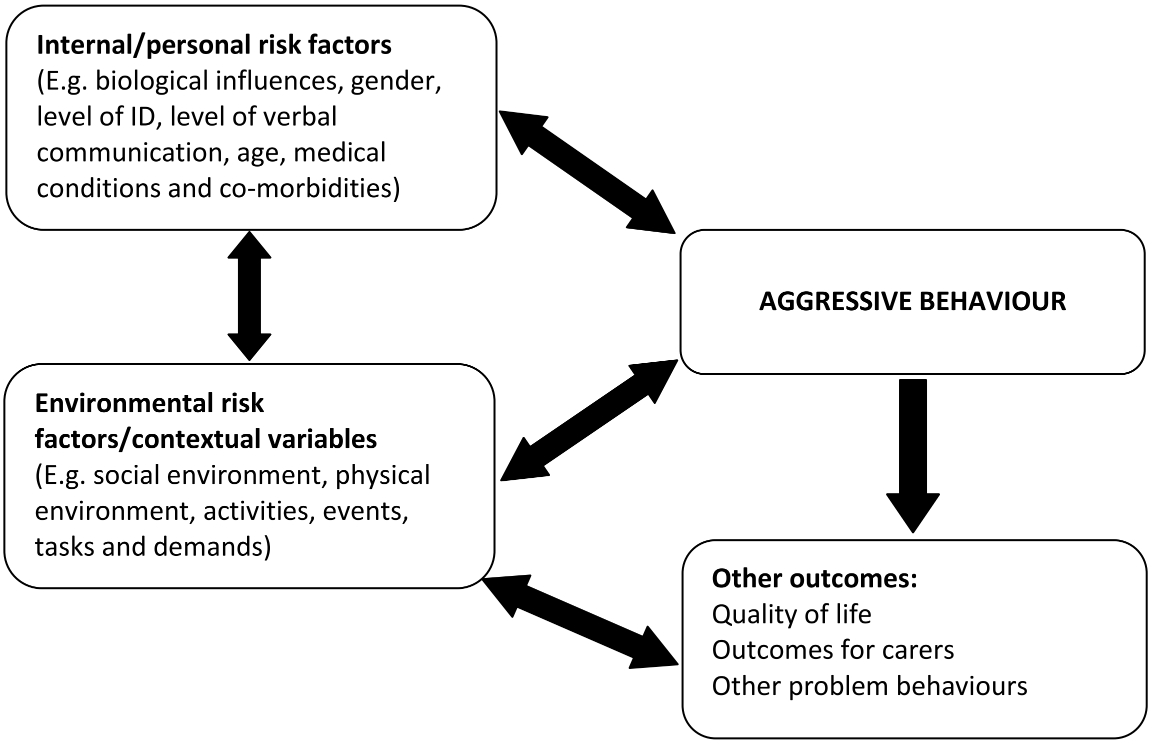
More specific features of environments have been reported in a few papers that address contextual variables and setting events. Similar to the functional literature, elements of the social environment are commonly implicated in precipitating aggressive behaviour, such as other people being too close or far away, crowded rooms or a lot of noise from others, negative interactions with others, requests by others or failure to have requests met (Embregts et al, 2009a; McGill et al, 2005; McAtee et al, 2004). Furthermore, variables relating to tasks and activities are also commonly cited including tasks the person finds difficult, doing nothing and waiting for things (McGill et al, 2005).

Aims

The study had a number of broad aims, driven by evaluation of the literature, to address current knowledge gaps. The literature indicates that aggressive behaviour has various internal and external determinants; the interplay between these factors triggering the behaviour. Interventions seek to modify some of these factors in an attempt to prevent or manage this behaviour (see Appendix 1 for a brief review of interventions). Aggressive behaviour may coincide with other challenging/problem behaviour and all such behaviours can impact on the person’s quality of life and those around them, especially carers. Furthermore, carers play an important role in determining and managing aggressive behaviour and are themselves features of the external environment. Figure 1 provides a proposed schema for this process; the present study aimed to examine each component of this process.

The underlying aim was to naturalistically study aggressive behaviour in a clinical cohort of adults with ID who exhibit aggressive behaviour of any severity, using a prospective longitudinal design. Longitudinal research allows change over time to be mapped and inference of causation by repeated measurement of variables (Vandenbroucke et al, 2007; Rajulton, 2001). This addresses the predominance of research in the field that has taken a cross-sectional/retrospective approach. For example, a key study reported by Crocker and colleagues (2006) has been criticised for its retrospective nature and lengthy time period studied which may have led to recall bias and inaccuracy in reporting (Benson & Brooks, 2008). Chronicity of aggressive behaviour was also investigated, as McClintock and colleagues (2003) suggest: studies of the chronicity of aggressive behaviour are severely limited in number. Chronicity in the present text refers to the prospective topography (type and severity) of aggressive behaviour. Of the limited existing longitudinal studies in the field, most focus on chronicity of SIB only, rather than including outwardly-directed aggressive behaviour and usually focus on persistence (presence or absence of a behaviour) instead of examining fluctuations in severity (Murphy et al, 2005). Therefore, the present study investigated both SIB and outwardly-directed aggressive behaviour (verbal aggression, property destruction and physical aggression to others) and collected data on severity of aggressive behaviour over a 12 month period.

Figure 1: Schema for aggressive behaviour



People with ID who exhibit aggressive behaviour in the UK are normally in contact with specialist health services for management of aggressive behaviour, namely, multi-disciplinary Community Learning Disability Teams (CLDTs) (McKenzie et al, 2011; Jess et al, 2008; Bouras and Holt, 2004; Emerson et al, 1991). However, there are no contemporary studies available describing the characteristics of a community-based clinic sample of adults who exhibit aggressive behaviour. Providing a description of the characteristics of such a clinic sample can help inform future service provision. Furthermore, contrasting the sample with the demographic profile of adults with ID from epidemiological studies can determine whether the sample is representative of adults with ID more broadly or whether certain characteristics are more prevalent in adults with ID and aggressive behaviour who are in receipt of specialist health services. Therefore, the study first aimed to describe the characteristics of such a sample, recruited from CLDTs.

Little research describes the topography of aggressive behaviour amongst a clinical, community–based sample of adults with ID. Benson & Brooks (2008) suggest 'identifying aggression types may clarify mixed results of previous research' (pp. 454) and cite the lack of description of topography and severity of aggressive behaviour in studies as a major obstacle in the field. Therefore, the present study aimed to describe the nature of aggressive behaviour amongst a large cohort in relation to both trajectory and topography. As Tenneij and Koot (2008) suggest, 'it is crucial to know what these behaviours actually look like' (p. 115).

Existing research tends to presume that aggressive behaviours persist over time; however, other research has indicated that remission in the short-term may occur (Cooper et al, 2009a, 2009b). As severity and persistence of aggressive behaviours in adults with ID may fluctuate, the present study aimed to follow-up participants with multiple data collection points to investigate how the behaviour manifests over time along with a range of other outcomes, such as quality of life and carer's outcomes. In this way, medium-term chronicity could be addressed. The author is not aware of any existing studies that have used a longitudinal design, with repeated follow-ups, to trace the trajectory of aggressive behaviour in detail over the course of a year. Many longitudinal studies track behaviour over a longer time period but with only one follow-up. The initial aim was to trace the trajectory of aggressive behaviour of the whole cohort with secondary aims to identify those who demonstrate a clinically significant improvement and to investigate whether the profile of these individuals differs from those who demonstrated no change or worsened.

A wide range of variables have been reported to be associated with aggressive behaviour in existing research, largely in terms of individual risk factors and point-prevalence of aggressive behaviour, however, very few studies have sought to identify personal and environmental factors associated with persistence of aggressive behaviour over time (Emerson & Einfeld, 2011; Totsika et al, 2008).

The present study therefore aimed to prospectively investigate such factors in relation to severity and type of aggressive behaviour. Information on the persistence of aggressive behaviour can facilitate the identification of factors that are associated with chronicity, allowing for a profile of risk markers to be established. The approach first identified individual risk factors and then investigated independent risk factors using multiple regression analyses to contribute towards developing an aetiological hypothesis for aggressive behaviour (Cooper et al, 2009a; 2009b).

Much research has focussed on personal, internal, stable or relatively stable characteristics as risk factors for aggressive behaviour or behavioural determinants of aggressive behaviour through functional analysis. Little research has considered environmental factors in relation to contextual variables (Darrow et al, 2011; Embregts et al, 2009a). Therefore, the present study sought to investigate a range of personal risk factors as well as external/environmental factors. Of the little research that has investigated contextual variables, much is with small sample sizes, has derived individual variables from the literature and expert professional opinion and not used formal empirical methods to categorise these variables. Therefore, the present study aimed to examine contextual variables which may ‘trigger’ aggressive behaviour using a bottom-up approach, based on carer’s reports of triggers for aggressive behaviour and by applying standard qualitative analysis methods.

Commonly, social variables are implicated in precipitating aggressive behaviour (Matson et al, 2011). Carers are themselves a key feature of the environment and research has demonstrated that carers can play a crucial role in reinforcing and maintaining aggressive behaviour. However, little research has explored carers’ understanding of determinants for aggressive behaviour, especially family carers, therefore, the present study sought to provide an insight into carers’ understanding of triggers to inform clinical work that may better support carers in delivering behavioural support plans based on professional functional assessment.

To summarise, the following were the aims of the study:

1. To recruit a cohort of adults with ID who exhibit aggressive behaviour of any severity and who are in receipt of specialist services from a CLDT for management of aggressive behaviour.
2. To follow-up the cohort for a period of 12-months, with three data collection points at six month intervals.
3. To describe the characteristics of a large clinic sample of adults with ID who exhibit aggressive behaviour.
4. To investigate the cross-sectional topography of aggressive behaviour across the cohort in relation to severity as well as types of aggressive behaviour and how these inter-relate.
5. To investigate the natural history (retrospectively) and 12-month trajectory (prospectively) of aggressive behaviour.
6. To investigate the 12-month trajectory of related outcomes, including severity of other problem behaviours, quality of life and carer's outcomes and to investigate the relationships between topography of aggressive behaviour and related outcomes.
7. To identify risk factors and associations with severity and type of aggressive behaviour over time, including prognostic risk factors.
8. To gain an insight into carers' understanding and experiences of contextual variables and motivations for aggressive behaviour.

Research Questions

The following were the research questions posed. The corresponding chapter in the thesis is given in box brackets. As current literature is lacking or inconclusive, no directional hypotheses are made, rather the study and analyses are exploratory.

1. What is the profile of a community-based cohort of adults with ID who exhibit aggressive behaviour of any severity and are in receipt of specialist services for aggressive behaviour? [Chapter 3]
2. What types of aggressive behaviour are exhibited by the cohort? [Chapter 4]
    a. What form do these behaviours take?
    b. How severe are they?
    c. How do they inter-relate in terms of presence and severity?
3. To what extent is aggressive behaviour chronic and persistent? [Chapter 4]
    a. What is the average age of onset?
    b. How does aggressive behaviour manifest over time?
    c. Does severity fluctuate over time?
    d. Do certain individuals demonstrate a clinically significant change in aggressive behaviour?
    e. Does the profile of these individuals differ from those who demonstrate no change or whose behaviour worsens over time?
4. How do other related variables manifest over time (severity of other problem behaviour, quality of life and outcomes for carers)? [Chapter 4]
5. Are certain personal, characteristics, including demographic variables (for example, gender, age, degree of intellectual impairment, place of residence, expressive verbal communication), co-morbid diagnoses/health conditions (for example, mental health conditions, ASD, epilepsy, sensory impairments, physical disabilities, genetic disorders and medical/physical health

conditions), and severity of other problem behaviour (for example, hyperactivity/non-compliance, lethargy/social withdrawal, stereotypic behaviour, and inappropriate speech) related to topography of aggressive behaviour? [Chapter 5]

6. Can a risk profile for chronicity of aggressive behaviour be established? [Chapter 5]
    a. Do certain personal characteristics predict topography of aggressive behaviour at six and 12-month follow-up?
7. What types of contextual variables and motivations elicit aggressive behaviour? [Chapter 6]
    a. What do carers interpret as triggering aggressive behaviour?
    b. How does this understanding relate to existing research?

CHAPTER 2: METHODOLOGY

Study design

The study utilised a naturalistic, longitudinal, mixed methods, cohort design employing questionnaire and assessment scale data collection via structured interviews with informants (paid care workers or family care givers) to collect both quantitative and qualitative data to investigate the natural history and trajectory of aggressive behaviour and surrounding issues in a clinical sample over a 12-month period. Interviews were conducted three times at six month intervals (see Figure 2). Data were collected on participant demographics/characteristics, situational/contextual variables, co-morbidities, topography of the target behaviour (including objective assessments), quality of life, and outcomes for carers.

The reporting in this thesis follows the STROBE statement which comprises 22 statements considered 'essential for good reporting of observational studies' (von Elm et al, 2007, p. 1624; Vandenbroucke et al, 2007).

Participants

Adults with Intellectual Disability

A clinical sample of adults (18 years and over) with ID was recruited via Community Learning Disability Teams (CLDTs). All individuals meeting the inclusion criteria within each clinical team identified for recruitment were invited to take part. As the study was interested in the effect of degree of ID, people with all levels of ID were eligible to take part, similarly with severity of aggressive behaviour.

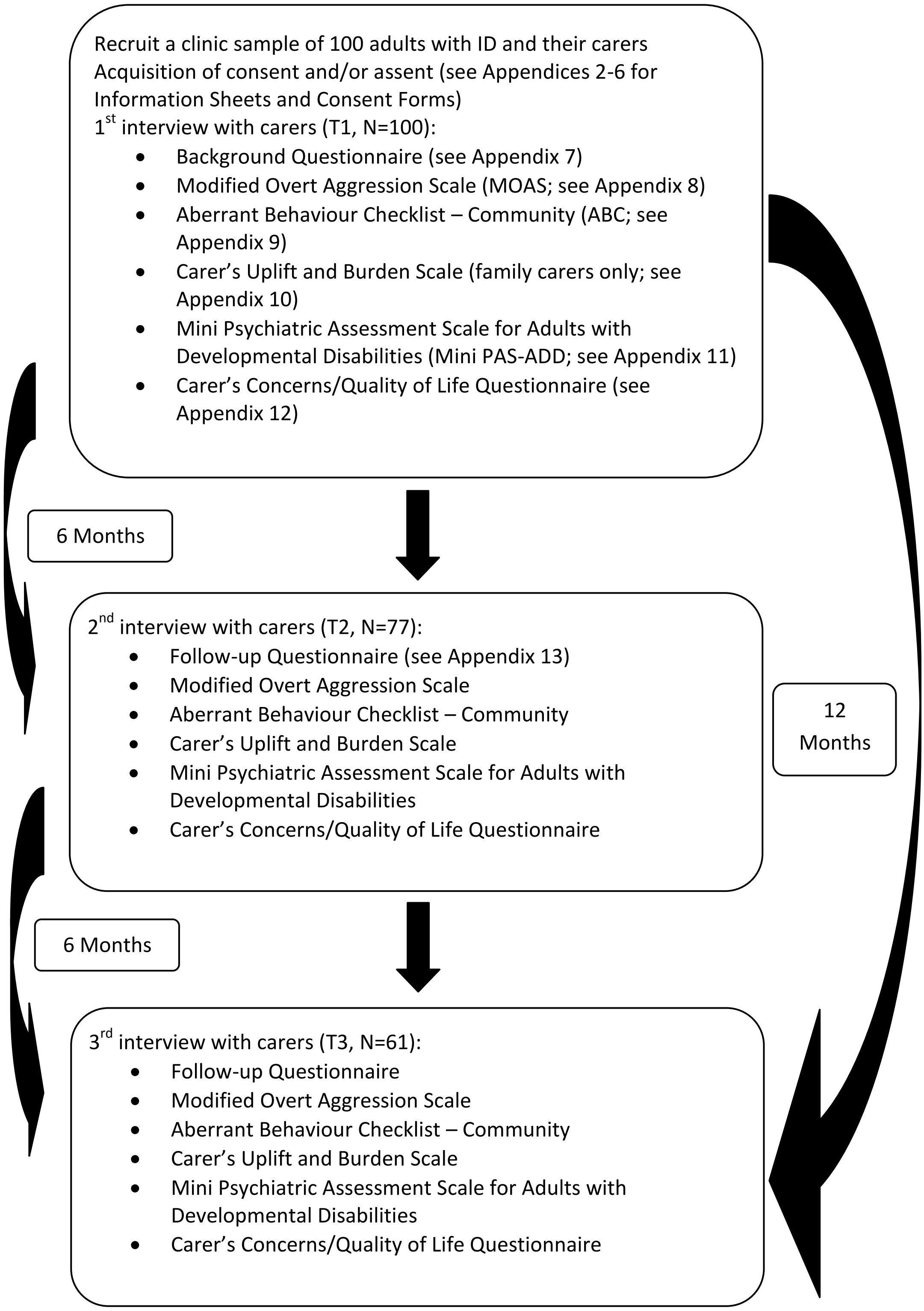
The sample size calculation sought to ensure adequate power to the primary statistical analyses, comprising multiple regression analyses to investigate the relationships between aggressive behaviour and putative risk factors in an attempt to model aggressive behaviour. It was anticipated that between three and four predictors would be entered into each multiple regression analysis so a sample size of 76-84 participants would be required to detect at least a medium effect (f_2=0.15) with statistical power of 0.8. Therefore, a target of 100 participants was established to allow 16-24% attrition. Brace and colleagues (2000) suggests that the absolute minimum number of participants required for a multiple regression is five times the number of predictor variables with 10 being favoured.

Diagnosis of ID was confirmed through a case note review of each potential participant as well as assessment during the interview (see Assessment Scales and Questionnaires section in this chapter). However, it is acknowledged that most would have administratively-defined ID and would not have received formal IQ and adaptive functioning assessments. It is possible, therefore, that some participants would have a higher IQ than the standard international cut-off for ID (<70, WHO, 2010). However, the sample benefits from ecological validity as it represents a clinic sample (see Chapter 3 for further discussion of the sample representativeness).

Carers

Whilst people with ID are termed ‘participant(s)’ throughout, carers were actively engaged in the data collection, acting as informants. Interviews were conducted with paid or family carers who knew the participant well. Every effort was made to identify a carer likely to remain in contact with the participant for the duration of the study.

Figure 2: Flow Diagram of the Study Process



Recruit a clinic sample of 100 adults with ID and their carers
Acquisition of consent and/or assent (see Appendices 2-6 for Information Sheets and Consent Forms)
1st interview with carers (T1, N=100):

- Background Questionnaire (see Appendix 7)
- Modified Overt Aggression Scale (MOAS; see Appendix 8)
- Aberrant Behaviour Checklist – Community (ABC; see Appendix 9)
- Carer's Uplift and Burden Scale (family carers only; see Appendix 10)
- Mini Psychiatric Assessment Scale for Adults with Developmental Disabilities (Mini PAS-ADD; see Appendix 11)
- Carer's Concerns/Quality of Life Questionnaire (see Appendix 12)

2nd interview with carers (T2, N=77):

- Follow-up Questionnaire (see Appendix 13)
- Modified Overt Aggression Scale
- Aberrant Behaviour Checklist – Community
- Carer's Uplift and Burden Scale
- Mini Psychiatric Assessment Scale for Adults with Developmental Disabilities
- Carer's Concerns/Quality of Life Questionnaire

3rd interview with carers (T3, N=61):

- Follow-up Questionnaire
- Modified Overt Aggression Scale
- Aberrant Behaviour Checklist – Community
- Carer's Uplift and Burden Scale
- Mini Psychiatric Assessment Scale for Adults with Developmental Disabilities
- Carer's Concerns/Quality of Life Questionnaire

Eligibility Criteria

The Person with ID should:

- Be aged 18 years or above upon case note inspection
- Have a diagnosis of ID recorded in their clinic notes (mild, moderate, severe or profound)
- Have a record of exhibiting aggressive behaviour (within the last six months) in their clinic case notes
- Receive professional help from a CLDT for their aggressive behaviour (within the last twelve months).

The Carers (Informants) should:

- Be aged 18 years or over
- Have capacity to consent to take part in the research.

Exclusion Criteria, the person:

- Does not have ID, despite receiving services from a specialist ID service
- Exhibits other problem behaviour with no aggressive behaviour, such as stereotypical behaviour
- Displayed aggressive behaviour in the past but does not currently display aggressive behaviour
- Has not attended a clinic appointment at a CLDT in the last year.

Target behaviour

A broad definition of aggressive behaviour was used to include physical and verbal aggression directed towards other people, SIB, and aggression directed towards property. These four categories of behaviour conform to the four categories outlined in one of the primary outcome measures

(MOAS). Crocker and colleagues (2006) identify that most studies of aggressive behaviour focus on more severe forms, however, milder forms can also act as a barrier to social inclusion and pose significant difficulties for the person and people around them. For this reason, no stipulation of severity of aggressive behaviour was imposed. The present definition of aggressive behaviour also conforms to the definition used in other pertinent studies within the field. For example, Crocker and colleagues (2006) define aggressive behaviour as ‘verbal and/or motor behaviour directed towards oneself, one’s environment or others... [which] can be manifested directly or indirectly and can be more or less planned’ (p. 654). In this way, no assumptions as to the function, motivations or intentions for behaviour were made. Other studies have used the definition for aggressive behaviour provided by the *Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation* (DC-LD, RCPsych, 2001) as a way of standardising studies within the field (e.g. Cooper et al, 2009a; 2009b). However, the definition stipulates that the behaviour is not caused by an underlying physical or mental illness. This is often difficult to ascertain, requiring a comprehensive psychiatric assessment that was not within the remit of this study. Furthermore, an aim of the study was to explore the relationships between aggressive behaviour, physical and mental illness. Therefore, all those who exhibited aggressive behaviour were eligible to participate and data on mental and physical health problems were also collected.

Data on the four types of aggressive behaviour were collected separately to allow for sub-group as well as whole group analyses. As Crocker et al (2006) suggest: it is important to consider different types of aggressive behaviour as they may associate differently with potential predictors.

Interventions

There was no experimental manipulation owing to the naturalistic nature of the study and no interventions were imposed. Therefore, the natural course of aggressive behaviour and associated outcomes were investigated. However, a range of interventions may have been introduced or on going as all participants were in contact with CLDTs for help managing the aggressive behaviour.

Recruitment Process

CLDTs known to the author or the Research Supervisor (SD) were offered the opportunity to be involved. These were predominantly consultant-led psychiatric outpatient clinics (n=9). Ten clinics were involved in recruitment which broadly covered the West Midlands (UK) area representing a large diversity including a combination of urban, suburban and more rural areas with various socio-economic statuses.

Review of Case Notes for those Attending Each Clinic to Identify Potential Participants

Every patient attending each clinic within the last year was identified and their case notes examined against the eligibility criteria. A standard form was used to make a record of each set of case notes inspected. The patient's gender, date of birth, age at inspection of case notes, and level of ID were recorded. Subsequent comparisons between all those attending the clinic and those recruited to the study assessed potential response bias.

The inclusion criteria were operationalised to facilitate systematic and consistent analysis of case notes. As the study aimed to prospectively trace aggressive behaviour in an active clinic sample, only those who had attended a clinic appointment in the last year were included. The time scale was kept relatively long to capture those still in contact with professionals but with infrequent follow-ups, as is often the case for this patient population. Similarly, only those who currently exhibit aggressive behaviour or who had a recent history of displaying aggressive behaviour were invited to take part. Therefore, each set of case notes identified at this stage were closely examined for documentation of aggressive behaviour within the last six months. This time scale was chosen to be suitably long as previous experience with clinic case notes indicates that people may have ongoing problems not mentioned in the notes at every appointment. For example, while the person’s behaviour is reported as stable at the last few clinic appointments, when this is investigated further the person’s stable behaviour may still include some aggressive behaviour.

A total of 1,645 adult patients who had attended a clinic appointment in the last 12 months were identified across the ten sites, of these 1,449 case notes (88%) were available to be inspected.

Letters of Invitation

Carers were invited to take part in the study through a letter of invitation addressed to managers of residential homes or relatives. The letter contained a reply slip, freepost return envelope and contact details of the researcher. After 6-16 weeks, a reminder letter was sent to those who had not responded. All positive responses were followed-up by letter or telephone contact with the nominated carer.

Consent and Agreement Process

Those who expressed an interest in taking part were sent an information pack containing separate information sheets for the carers and people with ID (see Appendices 2-4). It was deemed important to have separate information sheets with different levels of detail and wording. Furthermore, as Becker and colleagues (2004) highlight, it is important to educate individuals who support people with ID about research so that they can facilitate the person in making an informed decision about whether to participate.

The Carer Information Sheet followed national guidelines for information sheets for research (National Patient Safety Agency, National Research Ethics Service, 2007). The Participant Information Sheet also followed guidelines for producing accessible information for people with ID and included easy words, large font size and pictures to support the text. The intention was to facilitate potential participants to make an informed decision about whether they wanted to be involved in the study. In cases where the person lacked capacity, as much information as possible was provided to enable the person to express an opinion, in line with advice from the National Patient Safety Agency, National Research Ethics Service, UK (2011).

The information pack also included a Consultee Information Sheet (see Appendix 4) for situations where the person with ID lacked capacity (see Appendix 14 for the Assessment of Capacity Test) to provide consent to take part and therefore necessitated a consultee to be contacted. This sheet outlined the consultee's role under the Mental Capacity Act (MCA, 2005) informing them that they should act on behalf of the person who lacks capacity, in their best interests and only agree to the person being involved in the research if they believe that they would be willing if they had capacity. It also suggests that the consultee should be aware of any signs of resistance or indication from the person that they do not want to take part. In these cases, the consultee should not give their agreement. This meant that those who were deemed to lack capacity could still indicate whether or not they wanted to take part. The researcher also checked for such indications at the face-to-face meeting whereby consent and/or assent were verified and recorded. Consultees were identified following guidelines from the Department of Health (DH, 2008; see Figure 3). The aim was to consult with an individual who knew the person well.

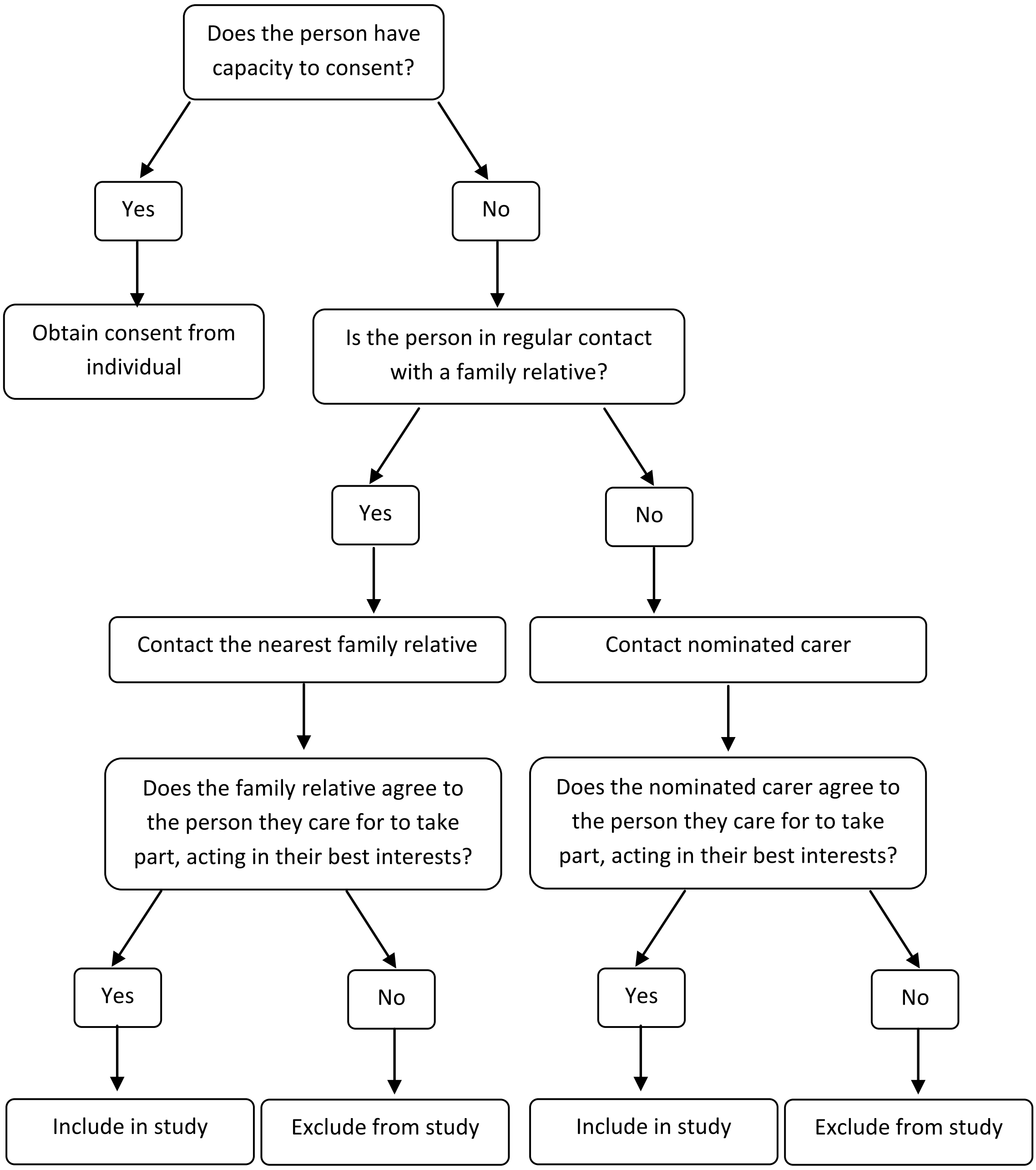
A meeting was arranged to meet the carer and the potential participant. A schedule guided the researcher through the various stages of the meeting, ensuring that the study had been fully explained and all questions were answered. Research on recruiting participants with ID highlights the need to allow ample time to explain the content of the research and to answer questions (Becker et al, 2004) so care was taken not to rush this process. During the meeting, the carer was asked to sign a Carer’s Agreement Form to record their consent to take part in the study (see Appendix 6). Participants with capacity were asked directly whether they consented to taking part in the study which was recorded on the Participant Consent Form (see Appendix 5). This was written in an accessible format with space to record acquisition of consent in different ways including space for behavioural consent to be witnessed where written consent was not practicable.

Methods

Interview Process

Each interview lasted approximately 90 minutes. All interviews were conducted by the same researcher (GU), thus reducing the risk of inter-investigator effects. In most cases, the interview was held at the home of the participant, which was also the carer’s home or place of work. Attention was paid to ensuring privacy so that discussions could not be overheard by others. A limit of one month before or after the due date of the follow-up interview was applied to ensure that interviews were completed within an acceptable time frame.

Figure 3: Flow diagram of consent and agreement process



The interviews took the form of a face-to-face structured interview. This format was chosen to help establish a rapport with carers, helping people communicate personal details and increasing the likelihood of participation in follow-up interviews (Clark-Carter, 2001). The interview schedule ensured uniformity across the interviews but allowed scope for carers to elaborate on issues they felt relevant (see Appendices 7-13). A range of questionnaires and standardised assessment scales allowed breadth and depth of data collection. The assessment scales facilitated objective and consistent measurement of a broad range of variables, as suggested by Brylewski and Duggan (1999) to capture the complex and contextually dependent nature of aggressive behaviours and to allow comparison between participants and within participants, over time.

It is common practice to use carers as informants in the field of ID research, however, it is acknowledged that this can introduce bias. Informants are often approached when the person themselves may have cognitive and communication deficits meaning that they do not understand questions posed, may not be aware of the behaviours under investigation or the impact of behaviours on others. Therefore, objective and validated outcome measures intended for use with informants were used to reduce this bias whilst also allowing the recruitment of people with all degrees of intellectual impairment and standardising the interview process throughout.

Assessment Scales and Questionnaires Completed During the Interview

The majority of measures were selected due to previous use in studies that have demonstrated their reliability to measure the intended construct, be sensitive to change over time and to allow for comparison with previous studies.

Background Questionnaire and Follow-up Questionnaire

A purpose designed questionnaire captured information on participant and carer characteristics (see Appendix 7). Basic information on carers was collected in terms of their relationship to and how long they had known the participant. Carers were asked to provide information on the participant's age, gender, expressive verbal communication (no language/words and phrases/full sentences), current residential accommodation, cause of ID, physical health problems/medical conditions, mental health problems, whether the participant had a diagnosis of ASD or epilepsy, and whether the person had physical disabilities or sensory impairments. Further information was collected on age when the participant first exhibited aggressive behaviour, age when medical help was first sought for the aggressive behaviour and triggers (contextual variables and motivations) for the aggressive behaviour. The questionnaire included a combination of tick boxes, with a fixed range of responses and open-ended questions.

A functional/adaptive behaviour checklist based on the ICD-10 (WHO, 2007) was used to categorise participants based on their level of ID. Whilst it is acknowledged that formal assessment should include an IQ test, it was outside the scope of this study. Carers were asked to provide the participant's IQ although none could provide the answer. The researcher was advised in the assessment of level of ID and the checklist was approved by a consultant psychiatrist specialising in ID. To further improve reliability, participants were categorised into two broad groups, namely, mild-moderate and severe-profound ID, as described in Chapter 5.

Each interview began with the background or follow-up questionnaire (see Appendix 13) which provided a general discussion about the person and their behaviour, helped the researcher to start to understand the person and provided an appropriate introduction to the interview. Subsequently, a suite of standardised assessment scales were administered each providing scores for a range of variables of interest. The primary outcome measures were two measures of aggressive behaviour, namely, the Modified Overt Aggression Scale (MOAS) and the Aberrant Behaviour Checklist (ABC). As Tsiouris and colleagues (2011) suggest, these two instruments are most commonly used to study aggressive behaviours. The following presents a summary of each assessment scale administered during the interviews along with details of the psychometric properties of each scale (where available).

Modified Overt Aggression Scale (MOAS)

The MOAS is a modified version of the Overt Aggression Scale (MOAS, Ratey & Gutheil, 1991; OAS, Silver & Yudofsky, 1991, see Appendix 8), which was developed to document aggressive episodes when they occur and to assess the effectiveness of interventions in the management of violent patients. This modified version is a retrospective instrument that improves the ease of administration. The MOAS has 16 classes of aggressive behaviour grouped into four subscales (verbal aggression, physical aggression against objects, physical aggression against the self and physical aggression against others). Each type of aggressive behaviour is rated by informants on a 5-point scale of increasing severity, from 0 for absent to 4, indicating the most severe type of behaviour. Brief examples of the types of behaviour which would qualify for each of the scores are provided.

The MOAS has been validated to be a practical and effective measure of aggression and has been used successfully to rate behaviour of people with ID via informant report (Ratey & Gutheil, 1991; Tyrer et al, 2008). A recent investigation of the psychometric properties of the MOAS in people with ID found it to be a reliable measure (inter-rater reliability intra-class correlation coefficient (ICC)=0.93 for total score; Oliver et al, 2007). Previous investigations using other patient populations have reported good inter-rater reliability for each subscale (0.85-0.94, Kay et al, 1988; 0.85-0.98, Kho et al, 1998). Furthermore, it has been suggested that the MOAS is user-friendly, does not require any formal training (Crocker et al, 2006; Bowers, 1999) and is a useful tool for monitoring aggressive behaviour among people with ID which can be used to assess trends over time (Burns et al, 2003; Knoedler, 1989).

The scores for each type of aggressive behaviour can be totalled to provide a total severity of aggression score. Whilst this total score has been used in some studies, it can be problematic as it affords equal weight to each sub-type of behaviour. In practice, physical aggression is commonly regarded as most severe and verbal aggression as less severe. The scores on the MOAS subscales can therefore be weighted through multiplication to provide a more accurate measure of severity (Crocker et al, 2006). To calculate the weighted MOAS score, the score for verbal aggression is multiplied by one, aggression against property multiplied by two, aggression against self multiplied by three, and aggression to other people multiplied by four, the scores are then totalled, to give a possible score of 0-40 (Crocker et al, 2006).

Aberrant Behaviour Checklist – Community (ABC)

The Aberrant Behaviour Checklist-Community (ABC; Aman et al, 1995, see Appendix 9) is a widely used scale with well established psychometric properties and consistently reported validity and reliability (Lundqvist, 2013; Unwin & Deb, 2008; O'Brien et al, 2001). It measures a wide range of problem behaviour over the month preceding assessment. The ABC was originally developed for use in institutions with adaptations made to create the ABC-Community for community settings, becoming one of the most widely used behaviour rating scales in the field of ID research (Rojahn et al, 2011). The ABC has been validated in a range of settings and rater sources (test-retest reliability r_s=0.96-0.99; inter-rater reliability r_s mean=0.63 across subscales; Aman et al, 1985) with good internal consistency (mean Cronbach's alpha across subscales=0.87; Rojahn et al, 2011). It has been shown to be a meaningful measure of intervention effects and initial assessments of people with ID and co-morbid mental illness (Shedlack et al, 2005) as well as for assessing problem behaviour in its own right (Aman, 2012).

The ABC has 58 behavioural items, rated by informants on a 4-point scale from '0=not a problem' to '3=severe problem'. The ABC has five empirically-derived factors with the 'irritability, agitation and crying' subscale (ABC-I) closely corresponding with the present definition of aggressive behaviour and incorporating similar behaviour as outlined in the MOAS. However, it does include additional items relating to being irritable, depressed mood, mood changing quickly, demands must be met immediately, and crying over minor annoyances and hurts. These are not directly relevant to aggression, however, given the proven factor structure of the ABC and the fact that ABC-I and weighted MOAS scores are closely correlated in the present sample at T1 (r_s=.77, p<.0001), the ABC-I is used as an additional measure for severity of aggression. The benefit of using the ABC-I is that it measures aggression over a longer time-scale, more directly measures severity of aggression with carers asked to rate severity on a Likert scale and has been widely used in research. This subscale has 15 items with a possible score of 0-45 with higher scores representing increasing severity.

The other four factors are labelled 'lethargy, social withdrawal' with 16 items and a potential score of 0-48; 'stereotypic behaviour' with seven items and a potential score of 0-21; 'hyperactivity, non-compliance' with 16 items and a potential score of 0-48; and 'inappropriate speech' with four items and a potential score of 0-12. Whilst some studies have summed the scores on each subscale to provide a total score (e.g. Tyrer et al, 2008), this is not a valid measure as it lacks construct validity and may potentially allow for cancellation between subscales (Aman, 2012). Therefore, subscale scores are used in the present study.

Carer's Uplift and Burden Scale

The Carer's Uplift/Burden Scale (Pruchno, 1990, see Appendix 10) was originally developed to measure perceived carer uplift and burden in spouse caregivers of people with mental health problems. Whilst not originally designed for carers of people with ID, it has recently been used successfully with this population in randomised controlled trials and is suitable in the present context as it is specifically designed for informants (Hassiotis et al, 2012; Tyrer et al, 2009). The questionnaire asks family caregivers to rate six uplift items and 17 burden items for the last four weeks on a three-point Likert scale from ‘not at all/never’ to ‘most of the time/often’. The scores for each construct are totalled to provide a possible score range of 6-18 for uplift and 17-51 for burden. The uplift items reflect the daily ‘pleasures or compensations afforded by life as a caregiver’ (Pruchno, 1990, p. 62). Items on the burden scale reflect the more negative psychological aspects of caring. Internal consistency for each construct is high (coefficient alpha=.80 for uplift and .89 for burden; Pruchno, 1990).

Mini Psychiatric Assessment Scale for Adults with Developmental Disabilities (Mini PAS-ADD)

Presence of mental health problems was assessed using the Mini PAS-ADD (Prosser et al, 1998, see Appendix 11) which was designed to provide information on psychiatric symptoms through semi-structured interview with informants and can be used by individuals who do not have a professional background in psychopathology (Moss, 2002). Carers were asked about the previous four weeks leading to assessment. The schedule is intended to be used as a screening instrument and to aid subsequent diagnosis by a suitably trained professional (Edwards, 2003), it can also be used to monitor the impact of interventions (Moss, 2002). The schedule is based on ICD-10 (WHO, 1994) diagnostic criteria and produces scores relating to commonly occurring Axis 1 psychiatric disorders, namely, depressive disorder, anxiety disorder, hypomania/mania/expansive mood, obsessive compulsive disorder (OCD), psychosis, unspecified disorder (including dementia and organic problems), and ASD (Moss, 2002). Thresholds are provided for each condition, where a participant reaches or exceeds the threshold, it is indicated that a psychiatric disorder may be present. The ASD section of the interview addresses the three core components of ASD (Wing, 1996) in three sub-sections relating to impairments in social interaction, communication and repetitive/stereotyped behaviour/interests. The threshold for all three subsections must be met for ASD to be indicated.

Prosser et al (1998) reported an overall correct classification rate of 91% for cases and non-cases when completed by consultant psychiatrists and 81% when completed by members of community support teams. Internal consistency, as measured by Cronbach's alpha, was at or above 0.6 for all subscales. Inter-rater reliability ranged from 0.32 to 0.65. Matson and colleagues (2012b), in a review of measurements of psychopathology in people with ID, conclude that there is 'an impressive amount of high quality research on the PAS-ADD. As a result, it is a very well established measure and it is clearly the measure for psychopathology for persons with ID in the United Kingdom' (p. 556).

Carer's Concerns/Quality of Life Questionnaire

The Carer's Concerns/Quality of Life Questionnaire is a clinical tool used by the Research Supervisor (SD) in his psychiatric outpatient clinic for people with ID (see Appendix 12). The questionnaire was designed to measure the level of concern experienced by someone caring for an adult with ID who exhibits aggressive behaviour and the quality of life of the person they care for against a number of items (see Appendix 15 for details of the development of the scale). The scale was intended to provide more objective and holistic measurements of quality of life in clinical settings in light of a paucity of good quality instruments for this population (Townsend-White et al, 2012). The questionnaire has two dimensions each with 8 items rated on a 5-point scale (scored 0-4). The scores for each scale are totalled to provide a concern score and quality of life score out of a maximum of 32, indicating the highest level of quality of life or concerns. As the reliability and validity of the scale had not yet been tested, data were collected during the first interviews to allow for analyses (see Appendix 15 for details of the scale development and testing).

The Carer's Concerns/Quality of Life Questionnaire was found to have very good test-retest reliability with an ICC of 0.81 for carer's concerns (range 0.46-0.83 across items) and 0.80 for quality of life (range 0.65-0.81 across items). Similarly, the scale had good inter-rater reliability with an ICC of 0.67 for carer's concerns (range 0.31-0.63 across items) and 0.63 for quality of life (range 0.31-0.65 across items). Internal consistency for each subscale was also good (Cronbach's alpha=0.85 for carer's concerns and 0.80 for quality of life; Split-half Spearman-Brown=0.81 for carer's concerns and 0.70

for quality of life). Furthermore, the scale showed good concurrent validity with measures of severity of aggressive behaviour and carer's outcomes with carer's concern.

Ethics

A favourable ethical opinion from the National Research Ethics Service (see Appendix 16) and approval from NHS Trust Research and Development Departments were obtained prior to recruitment. All data were kept anonymous through the use of an identification number assigned to each case. Personal details attached to the identification numbers were kept confidential and only known to the researcher. The identification number was used on all data collection paperwork and during data analysis. Written consent forms were completed by all carers. Where possible, verbal and/or written agreement from service users was also secured, as previously discussed. All information about the project was provided to potential participants and their carers in an accessible format.

Data Analysis

An overview of the statistical analyses used throughout the thesis is presented here; further detail can be found within relevant chapters. Details on the qualitative analysis used in Chapter 6 are presented in the corresponding chapter.

All quantitative data were entered into IBM SPSS Statistics Version 19.0 databases to allow for analysis. The databases were double-checked against the raw data to ensure accuracy of input. Initially, the distributions of the data were examined using stem and leaf plots, histograms and normality tests (Shapiro-Wilk). Both parametric and non-parametric analyses were used as some variables did not approximate the normal distribution or contravened the assumptions of parametric tests. Transformations of non-normal data were attempted but still resulted in non-normal distributions particularly with MOAS scores. Previous research using weighted MOAS scores has reported similar difficulties (Tyrer et al, 2008; Crocker et al, 2006). Exploratory data analyses sought to summarise and describe the data. Appropriate measures of central tendency and dispersion are presented, depending on the distribution of the data (for example, where the data approximated a normal distribution, means and standard deviations (SDs) are presented and where the data did not follow the normal distribution or may be affected by outliers, medians and inter-quartile ranges (IQRs) are presented).

Data to two decimal places are presented throughout, except for p-values where additional decimal places are required to indicate the specific level of significance or where this level of accuracy is redundant. The critical probability level (alpha) was set at 0.05 throughout the analyses, except where adjusted for multiple comparisons. Missing values were dealt with on a test-by-test basis with data excluded pair-wise. All analyses were two-tailed to reflect the non-directional hypotheses and exploratory nature of the study. As the study is observational rather than experimental, correlation-based analyses were favoured to analyse the data as these are more suited to the research design (Field, 2005); however, where relevant, other analyses were used to explore significant differences in the data.

For continuous data, tests for significant differences between two groups were analysed using independent sample t-tests and Mann-Whitney tests, depending on whether the data met the assumptions for a parametric test. Similarly, analyses of variance (ANOVA) and Kruskal Wallis tests were used where there were more than two groups. Tests for significant differences in scores on the outcomes measures over time (within person, over the three data collection points) were analysed using one way repeated measures ANOVAs or Friedman's ANOVAs, including planned comparisons (repeated measures t-tests or Wilcoxon signed-rank tests) with p-values adjusted using Bonferroni's correction, see Cupples et al, 1984).

Pearson's chi-square tests were used to investigate the independence of categorical variables except where cells had an expected count of less than five, contravening the assumptions of the test and resulting in a loss of statistical power; Fisher's Exact Tests were utilised in these circumstances. Pearson's and Spearman's correlation analyses were performed to investigate relationships between continuous or ordinal data and point-biserial correlation was used where one variable was binary.

The results of univariate analyses of individual variables informed multiple regression analyses. Multiple linear regression analyses were used to investigate the relative predictive utility of variables for continuous outcomes, such as scores on the outcome measures. Logistic regression analyses were used for dichotomous outcomes such as presence or absence of specific behaviour types. In the case of logistic regression analyses, pseudo R^2 estimates are presented, namely Cox and Snell's and Nagelkerke's. Both have limitations as they tend to be lower than traditional R^2 measures, however, Nagelkerke's is a correction of Cox and Snell's to allow the coefficient to vary from zero to one, being more representative of traditional R^2 (www.strath.ac.uk).

Forced entry regression analyses were performed as they were deemed the most appropriate given the circumstances: all variables under investigation were informed by existing research and theory, however, evidence was lacking that could have informed a hierarchical analysis (Field, 2005; Osborne et al, 2002; Brace et al, 2000). The data for each analysis were checked to ensure they met the assumptions of the test, namely homogeneity of variance of errors (homeoscedasticity), normal distribution of residuals/errors, linearity, no multicollinearity, with no extreme cases exerting undue influence of the model (Field, 2005; Osborne et al, 2002). Residual plots, distance statistics, casewise diagnostics, frequency tables and correlation tables were used to examine conformity with these assumptions.

Literature Review

To identify existing literature relevant to the topic of the thesis, systematic literature searches were conducted and regularly updated in four electronic databases of journal articles (Medline, PsycInfo, Embase and Cinahl). The search terms defined the population and condition under study, namely, adults with ID with aggressive behaviour. A wide variety of synonyms were used for each element of the search and terms were mapped to database indexing such as Medical Subject Headings. The majority of search terms were truncated allowing for different permutations of the words. Limits were applied in each database to restrict the search to humans, adults and English language abstracts. Each paper identified by the search was scrutinized for its relevance in each chapter of the thesis, where numerous papers were identified, more pertinent, recent or better quality articles were selected for inclusion. The electronic database searches were supplemented with hand searching and cross referencing of pertinent articles and journals. Whilst this approach avoided bias due to its systematic nature, it should be acknowledged that the literature reviews are not all-inclusive and may have omitted some relevant papers.

CHAPTER 3: CHARACTERISTICS OF THE COHORT AT TIME OF FIRST INTERVIEW

Participant Characteristics at T1

Data on a range of participant characteristics were collected at the time of the first interview (T1). The participant variables comprise two broad categories, namely, participant demographics and co-morbid diagnoses/medical conditions.

Participant Demographics

Table 2 provides a summary of the demographics of the cohort at T1. The majority of participants were male, had severe ID and utilised expressive verbal communication. Mean age was 37.12 years (SD=13.32) and median age was 34 years (IQR=22). The ages were skewed towards younger age groups (skewness=0.686, z=2.81, $p<0.01$). The majority of participants were living in community-based group homes, with 24-hour support whilst only seven lived in their own home with or without support from services. One participant lived at a residential college during term time and in the family home during holidays.

Co-morbid Diagnoses and Medical/Health Conditions

Table 3 provides a summary of co-morbid diagnoses, known to the carer and screened for by the Mini PAS-ADD at T1. Table 4 presents a summary of the number of participants with each medical/physical health condition and the numbers with multiple health conditions.

According to the carers, ASD was common among the sample; there were fewer potential cases of ASD identified by the Mini PAS-ADD. Carers were aware of a diagnosed mental health problem in 34 participants, the most common being depressive disorder (n=15). Eight participants had a mental health problem that did not fall into any of the stipulated categories: four had attention deficit hyperactivity disorder (ADHD), two personality disorder (one obsessional and one antisocial), and two Tourettes/tic disorder. Some participants were diagnosed with multiple mental health problems (n=8). These reported figures differ from the number of potential cases indicated by the Mini PAS-ADD.

The majority of participants had various medical/health conditions, the most common being; obesity/being overweight; gastrointestinal problems (including indigestion/reflux/ constipation/irritable bowel syndrome/colitis disorder); and skin problems. Half the cohort had multiple medical conditions and twenty-seven participants had medical conditions that fell outside the above categories. The most common was curvature of the spine (n=4), followed by the person requiring a colostomy or catheter (n=3), an underactive thyroid (n=2), and raised cholesterol (n=2).

Cause of Intellectual Disability

The majority of carers (76%) did not know the cause or origin of ID; only 24 carers could provide a definitive cause. In nine participants, the cause was due to a known genetic disorder. Fifteen carers suggested the ID was caused by a pre, peri or post-natal brain injury or cerebral palsy. In one, this was caused by encephalitis and in another it was caused by Lennox Gastaut syndrome/infantile seizures. Some carers reported a queried cause for ID in the person they cared for (45%), the most common being traumatic birth (8%) and an unknown genetic or hereditary cause (7%). Three carers suspected the cause was due to childhood inoculations, however, in each case, this had not been confirmed.

Table 2: Participant demographics at T1 (N=100)

Characteristic		**Number**
Gender	Male	63
	Female	37
Age group (n=98)a	18-19	3
	20-29	31
	30-39	28
	40-49	17
	50-59	12
	60-69	5
	70-79	2
	80+	0
Mean Age	37.12 (SD: 13.32; range: 19-73)	98[a]
Place of residence	Community-based group home	53
	Family home	39
	Own home/supported living	7
	Residential school/college	1
Ethnicity	White - British	87
	Minority ethnic group	13
Marital status	Single/never married	93
	Married/living with partner	5
	Separated/divorced	2
Level of ID	Mild	23
	Moderate	32
	Severe	41
	Profound	4
Expressive verbal communication	Full sentences	45
	Words and phrases	30
	No language	25

[a] Data were not available for all participants.

Table 3: Co-morbid diagnoses at T1 (N=100)

Diagnosis		Number according to carer	Number according to Mini PAS-ADD
Genetic syndrome	Down syndrome	6	-
	Fragile X syndrome	1	-
	Rett syndrome	1	-
	Smith Magenis syndrome	1	-
Epilepsy	No epilepsy	65	-
	Suspected epilepsy, not confirmed	4	-
	Diagnosed epilepsy	31	-
Visual impairments	No visual impairment	53	-
	Requires glasses	43	-
	Registered blind/partially sighted	4	-
Hearing impairments	No hearing impairment	94	-
	Some problems with hearing	4	-
	Registered deaf	2	-
Physical disabilities	No physical disabilities	73	-
	Mild-moderate disabilities	21	-
	Severe-profound disabilities	6	-
Autism Spectrum Disorder (ASD)	No ASD	39	75
	Suspected ASD/autistic features	16	-
	Diagnosed ASD	41	24[a]
	Diagnosed Aspergers	4	-
	Impairments in social skills	-	42
	Impairments in communication	-	51
	Repetitive and stereotyped behaviour/interests	-	45
Mental health problems (excluding ASD)	No mental health problem	66	49
	Diagnosed mental health problem	34	51
	Depressive disorder	15	6
	Anxiety disorder	4	30
	Hypomania/mania/bipolar disorder	5	5
	Obsessive compulsive disorder (OCD)	3	26
	Psychosis/psychotic disorder	9	9
	Other mental health problem	8	2

-Not assessed by Mini PAS-ADD or carer.

[a] Data were not available on 1 participant, met all three subscales

Table 4: Medical/physical health conditions at T1 (N=100)

Medical/physical health condition	Number
Medical/physical health condition present	82
No medical/physical health condition	18
Obesity/overweight	30
Gastrointestinal problems	27
Skin problems/eczema/dry skin/rash	23
Recurrent infections (excluding UTIs)	10
Allergies/hay fever	10
Asthma	9
Urinary tract infections (UTIs)	9
Arthritis/osteoporosis	8
Dental conditions	7
Underweight/malnutrition	5
Dysphagia	4
Hypertension/raised blood pressure	3
Diabetes	3
Impacted ear wax	2
Other medical/health condition	27
Multiple medical conditions	50
2 medical conditions	22
3 medical conditions	13
4 medical conditions	13
5 medical conditions	2

Characteristics of Carers

Table 5 presents a summary of the demographic profile of the carers for each interview. The majority of carers were female (n=81; 81%). At T1, all the carers had known the participant for some time (range: 4 months – 56 years). Only three carers had known the person for less than a year. The mean length of time the carer had known the participant, across all participants was 14.69 years (SD=12.36). Thirty-eight carers had known the participant from birth (all family carers). Of those who had not known the person since birth, the mean length of time the carer had known the participant was 6.37 years (SD=5.18; range= 4 months – 20 years).

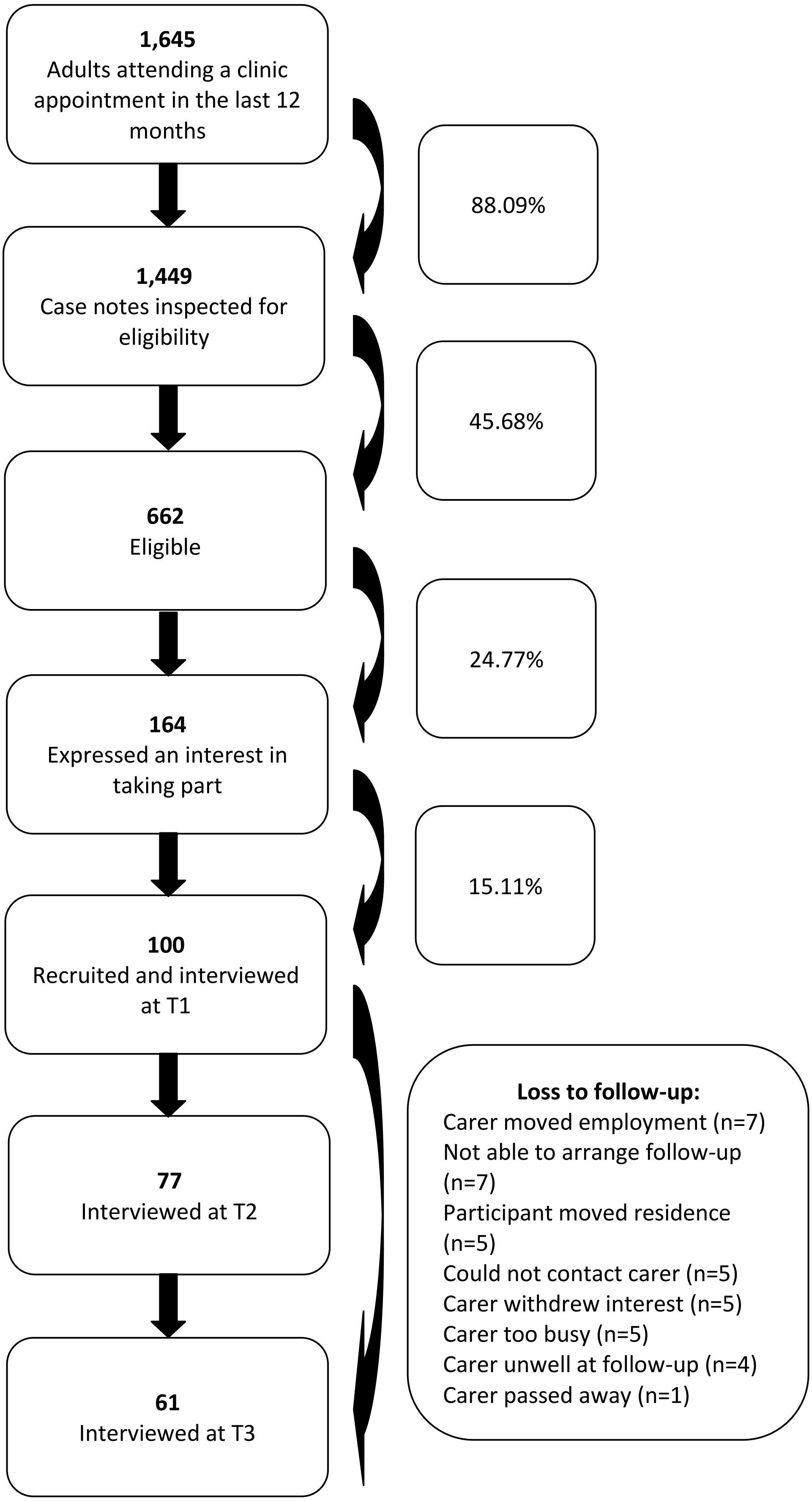
Table 5: Demographic profile of carers for each interview (N=100)

Type of carer	N (%)
Paid care worker	**56 (56.00)**
Female	46 (82.14)
Male	10 (17.86)
Home leader/manager	32 (57.14)
Direct care workers/key workers	24 (42.86)
Family carer	**44 (44.00)**
Female	35 (79.55)
Male	9 (20.45)
Parent	42 (95.45)
Sibling	2 (4.55)

Recruitment to the Study

The recruitment period lasted 27 months, from 11th January 2008 to 11th April 2010. T1 interviews were conducted between 21st February 2008 and 21st April 2010, T2 9th October 2008 to 20th October 2010 and T3 19th March 2009 to 10th March 2011. Figure 4 presents the flow of potential participants and participants through the study. Only 15.11% of eligible individuals were recruited to the study. Whilst this rate appears rather low, the difficulties surrounding recruiting adults with ID to research studies are well-documented in the literature and are discussed in more detail in Appendix 17.

Figure 4: Flow of recruitment and participation in the study



Representativeness of the Study Sample to the Clinic Population from which it was Recruited

The demographic profile of the clinic population was compared with those eligible and those recruited. Level of ID was available for 277 patients (16.8%). The categories for level of ID had to be extended to include mild-moderate, moderate-severe and severe-profound to reflect the diagnoses stated in the case notes. Table 6 provides summary statistics for all those attending a clinic appointment within the last 12 months, those who exhibited aggressive behaviour, and those who were recruited to the study.

Mann Whitney tests indicated that those who were eligible were significantly younger than those who did not exhibit aggressive behaviour and were therefore not eligible (U=170895, p<.001). Similarly, there was a significant difference in age between those who were and were not recruited (U=41264.50, p=.01). There was also a significant difference in age between those who were eligible but were not recruited and those recruited to the study, however, this ceased to be statistically significant after applying the Bonferroni correction for multiple comparisons (U=18342.50, p=.049).

Pearson's chi-squared tests indicated that there were no significant differences in gender breakdown across the groups (p<.05). Further chi-squared tests analysed whether there were any differences in the proportions of levels of ID for each group. These tests revealed no significant differences between those recruited and those not recruited or those recruited and those eligible but not recruited, however, tests to compare all groups could not be performed due to under-representation in some groups. Those eligible (who displayed aggressive behaviour) tended to have more severe ID, however, this association failed to reach statistical significance after applying the Bonferroni correction (X^2 (6)=13.71, p=.03).

Table 6: Characteristics of all those attending a clinic appointment, those eligible to be included in the study and those recruited

Characteristic		**All those attending an appointment** **N=1645**	**Those eligible (who display aggressive behaviour)** **N=662**	**Those recruited** **N=100**
Age[a]	Median (IQR)	41 (24)	39 (24)	34 (20)
	Range	18-94	18-86	19-80
Gender[a]	Male (%)	991 (60.5)	404 (61.03)	63 (63)
Level of ID[a]	Borderline (%)	1 (0.4)	1 (0.72)	0
	Mild (%)	60 (3.6)	19 (13.77)	3 (13.64)
	Mild-moderate (%)	9 (0.5)	4 (2.90)	1 (4.55)
	Moderate (%)	104 (6.3)	58 (42.03)	9 (40.91)
	Moderate-severe (%)	11 (0.7)	4 (2.90)	1 (4.55)
	Severe (%)	91 (5.5)	51 (36.96)	8 (36.36)
	Severe-profound (%)	1 (0.1)	1 (0.72)	0
	Profound	0	0	0

[a] Data were not available for all participants

Attrition

The six-month and 12-month attrition rates were 23% and 39% respectively. The main reasons for loss to follow-up were paid carers moving employment and difficulties in finding a mutually convenient time and date for the follow-up interview within the stipulated one month window either side of the interview due date. (see Figure 4 and Appendix 17 for a detailed discussion of attrition).

Analyses were conducted to examine whether there were any significant differences in the characteristics of those who were lost to follow-up and those who completed the 12 month study. The variables under consideration were type of carer (family/paid), participant's age, participant's level of ID (mild-moderate/severe-profound), participant's place of residence (family home/non-family home), participant's level of verbal communication (verbal/non-verbal), presence of co-morbid diagnoses (present/absent) and severity of aggressive behaviour at T1 (MOAS and ABC-I scores). There were no significant differences between those lost to follow-up and those who completed the study ($p<0.05$).

Discussion

Extensive data on participant characteristics were collected at T1 to profile the cohort. These data were used to compare the present sample with results from epidemiological studies to examine the representativeness of the cohort (see Appendix 18 for further details).

Characteristics of the Carers

The majority of carers interviewed were female, only 19 carers were male. This reflects the trend in care work which remains dominated by female staff members and other studies have reported a similar weighting towards female staff members (83%: Gray-Stanley & Muramatsu, 2011). The preponderance of mothers as primary family carer is also representative of current trends (Grant & Whittell, 2000).

At T1, only three carers had known the participant for less than a year and one carer had known the participant for only four months. However, this carer still had enough knowledge to respond to the questions in the interview as most were based on current/recent circumstances and thus did not require historical knowledge of the participant. As most carers had known the person for some time prior to interview and were a stable feature in the participant’s lives, it increased the likelihood that they would still provide care for the person at follow-up and could therefore participate in the follow-up interviews, providing consistency in ratings over time.

Prevalence of Aggressive Behaviour

Around 46% of case notes indicated that the client might be eligible to participate in the study suggesting an administrative six-month prevalence of aggressive behaviour among adults with ID who are in contact with CLDTs of around 46%. Studies investigating prevalence and incidence of aggressive behaviour report varying rates (see discussion in Chapter 1). Crocker et al (2006) used a comparable definition of aggressive behaviour (MOAS score of 1 or above) and reported a 12-month prevalence rate of 51.8% among 3,165 adults with ID receiving specialist services in Canada. Prevalence rates of problem behaviour have suggested rates of around 60% (Deb et al, 2001a; Smith et al, 1996; Jacobsen and Janicki, 1985; Koller et al, 1983) whereas studies of challenging behaviour report prevalence figures of around 10-15% (Lowe et al, 2007a; Emerson et al, 2001a). The present rate is therefore comparable with other studies considering that the sample was largely drawn from psychiatric services, there were no limits on severity of aggressive behaviours, and the breadth of the definition of aggressive behaviour. However, direct comparisons remain difficult due to the wide range in definitions, samples and methods used in epidemiological studies.

Representativeness of the Study Sample

The study sample represents a clinic-based sample of those known to specialist services (largely psychiatric services). In order to comment on the representativeness of the sample to more general populations, and therefore the generalisability of the results, comparisons of the demographic profiles of various samples were made using data from published large-scale epidemiological studies (see Appendix 18 for further details). Comparisons are also made in relation to the demographic profile of the clinic population from which the sample was drawn.

Age

The ages of the participants were skewed towards younger ages in comparison with the normal distribution. When compared to an epidemiological study (Emerson et al, 2011a), ages of the sample also tended to be younger than the whole population of adults with ID in England, and similarly to those known to health and social care services. Similarly, the present sample is younger than a large sample of adults receiving specialist psychiatric services (Bhaumik et al, 2008a). Sigafoos and colleagues (1994) presented a graph of the age distribution of their sample of individuals with ID and aggressive behaviour. Whilst their sample included children, the majority of the sample was in the

20-30 years age group, followed by 30-40 years old, demonstrating the same pattern as in the present sample.

The same trend for younger ages in the sample was observed when compared to the whole clinic population from which the sample was drawn. Those who were eligible to take part in the study, with aggressive behaviour indicated in their clinic notes, were younger than those who did not show aggressive behaviour. This finding compliments previous research, suggesting that prevalence of aggressive behaviour is associated with young to middle-age adults (e.g. Tyrer et al, 2006; Wisely et al, 2002; Deb et al, 2001a; Borthwick-Duffy, 1994; Collacott et al, 1998b). The age of the study sample was comparable to all those who were eligible to take part, indicating that the sample is representative of the clinic population with aggressive behaviour.

Gender

The present sample has a higher proportion of males to females (63% male). This is reflective of population trends whereby it is estimated that over 58% of the population of adults with ID are male (Emerson et al, 2011a) and similarly when compared to adults with ID in receipt of psychiatric services (57%; Bhaumik et al, 2008a). However, the proportion of males in the present sample remains higher. When compared to a large sample of adults with aggressive behaviour, the proportion of males is comparable with only 1 percentage point difference (64%; Sigafoos et al, 1994). This finding compliments previous research that reports aggressive behaviour as being more prevalent in males (e.g. Tyrer et al, 2006; Harris, 1993). However, other research has found no gender difference (e.g. Wisely et al, 2002; Nøttestad & Linaker, 2001; Collacott et al, 1998b) and others have reported certain types of aggressive behaviour to be more common in females (e.g. Cooper et al, 2009b; Crocker et al, 2006; Deb et al, 2001a) or in males (Crocker et al, 2006). These differences may reflect methodological differences in studies, especially in relation to definitions of aggressive behaviour, indicating that further research is needed to investigate gender associations with such behaviour.

The gender profile of the sample is representative of the clinic population from which it was drawn as well as all those who were eligible to take part. This indicates that there is no gender difference between those attending specialist clinics presenting aggressive behaviour, and those attending the same clinics but not presenting aggressive behaviour, thus supporting the notion that there is no overall link between gender and prevalence of aggressive behaviour.

Level of Intellectual Impairment

The majority of the sample had intellectual impairment in the mild to moderate range (55%). This is in contrast to the sample of adults receiving psychiatric services, reported by Bhaumik and colleagues (2008a) in which the majority had severe to profound ID and only 27.9% had mild to moderate ID. However, the distribution of ID reported by and Bhaumik and colleagues (2008a) appears weighted towards more severe levels and therefore may not be representative itself, perhaps because the authors included inpatients in their study. When the profile of intellectual impairment is compared to that of a sample of individuals with aggressive behaviour (Sigafoos et al, 1994), the breakdown is more comparable showing more similar numbers with mild to moderate and severe to profound ID. However, the present sample has a higher proportion of people with mild ID, possibly because the sample reported by Sigafoos and colleagues (1994) included those living in institutions, indeed, the authors found that more severe ID was associated with living in institutions and large group homes. No differences were observed in profile of ID when the sample was compared to the clinic population from which it was drawn, however, those eligible tended to have more severe ID. Existing research reports mixed results however, aggressive behaviour is often considered to be associated with increased degrees of intellectual impairment (see Chapter 1 for a discussion of the literature).

Place of Residence

The majority of participants resided in community groups homes (53%) with 39% living with family. The proportion living in residential homes is comparable to that reported by Bhaumik and colleagues (1998a; 27.4%) based on a large sample of adults receiving psychiatric services in the East Midlands. However, the present rate of people living with family is higher and similarly, higher than rates based on all adults with ID known to services living in England (Emerson et al, 2011a). This may reflect selection bias with family carers being more willing to participate in the study. Furthermore, in situations where the participant lacked capacity to consent, a consultee was approached to act in the best interests of the participant (see Chapter 2). As recommended by the Department of Health, UK (2008), family members were approached to act as consultee where possible thus making the recruitment process more straightforward when a participant lived with family. Where the participant did not live with family nor had contact with family members, the role of consultee may have proved more difficult to adopt for some paid carers. Such recruitment issues are discussed in more detail in Appendix 17.

Co-morbid Diagnoses and Medical/health Conditions

A large majority of the sample had a co-morbid medical condition or physical health problem (82%), the most common being epilepsy, obesity and gastrointestinal problems. Similar findings were reported in a large-scale study of general practice registers in the Netherlands, in which only 12% of people with ID showed no health problems compared with 21% of those without ID (van Schrojenstein Lantman-De Valk, 2000). Some conditions may be related to aetiology of ID (van Schrojenstein Lantman-de Valk, 1997; see O’Hara et al, 2010 for detailed reviews of the evidence on ID and ill health). The Learning Disabilities Observatory supported by the Department of Health, UK (Emerson et al, 2011b) reviewed research into standards of health experienced by people with ID and reported that people with ID have poorer health than non-disabled peers and that to an extent, these discrepancies are avoidable, thus representing health inequalities. A systematic review of health checks for people with ID, reported that between 51% and 94% had previously undetected health conditions (Robertson et al, 2011). An earlier systematic review identified a range of health problems that were more prevalent in people with ID than the general population including epilepsy/seizures, diseases of the skin, sensory loss, psychiatric disorders and obesity (Jansen et al, 2004) and a more recent review concluded that people with ID continue to have poorer health outcomes than the general population (McCarthy & O'Hara, 2011). An international study, collecting data on health conditions of 1,269 individuals with ID across 14 European Union countries, indicated that obesity, epilepsy, mental health problems, allergies and constipation were highly prevalent (Martinez-Leal et al, 2011).

Rates of 8.8% for obesity among people with ID have been reported with an additional 4.1% being overweight (van Schrojenstein Lantman-de Valk et al, 2000). However, these data are based on General Practice registers and may underestimate prevalence. A study reporting on health conditions identified through health checks or health screening reported a rate of 36%, indicating that obesity may have been previously undetected (Marshall et al, 2003). This prevalence figure is comparable with the rate of obesity observed in the present sample. Figures for obesity in adult British men and women have been reported to be 17% and 21% respectively (Jebb, 1998, cited in Marshall et al, 2003). Prevalence of obesity has been consistently reported to be higher in adults with ID than the general population (e.g. Hamilton et al, 2007; Melville et al, 2007; van Schrojenstein Lantman-De Valk et al, 2000; Martin et al, 1997). However, more recently, Bhaumik and colleagues (2008b) reported obesity to be higher in adult females with ID only.

Prevalence rates for epilepsy between 11-24% have been reported (Jansen et al, 2004), and rates of epilepsy have been reported to be at least 20 times higher among people with ID than the general population (Emerson et al, 2011b). The rate of epilepsy among the present sample is higher than previously reported; however, it is comparable to the study by Sigafoos and colleagues (1994) which showed the rate of seizure disorder to be 37% among a sample of adults with ID and aggressive behaviour. Whilst studies have indicated that there is no relationship between epilepsy and presence of aggressive behaviour (Buono et al, 2012; de Winter et al, 2011; Poppes et al, 2010; Cooper et al, 2009a; Cooper et al, 2009b; Jones et al, 2008; Matthews et al, 2008; Ring et al, 2007; Tyrer et al, 2006; Deb et al, 2001a; Espie et al, 2003; Collacott et al, 1998b; Aman et al, 1995), epilepsy appears to be overrepresented in the present sample. A relationship has been demonstrated in other studies between specific subgroups of people with epilepsy and aggressive behaviour (Espie et al, 2003; Deb & Hunter, 1991), however, most indicate no clear relationship. The inflated rate of epilepsy may be due to the clinical nature of the sample, which was predominantly recruited from psychiatric services. Co-morbid epilepsy could have increased the likelihood of contact with services as clients may require medication for the management of epilepsy.

It has been found that around 7.1 % and 3.1% of people with ID have gastric and oesophageal diseases or chronic urinary tract infections (UTIs) (van Schrojenstein Lantman-de Valk et al, 1997). The rates of these health conditions are higher in the present sample. However, as these data are based on primary health care registers, and owing to studies that report a high level of undetected health need in people with ID, these figures are likely to be underestimates. Furthermore, research has indicated that these conditions may in fact be associated with aggressive behaviour (de Winter et al, 2011).

The Mini PAS-ADD indicated that 51% of the sample may have some form of mental health problem, the most common being anxiety disorder and OCD. Recently, Tsiouris and colleagues (2011) investigated prevalence of psychiatric disorders in a community-based sample of 4,069 adults with ID receiving specialist services in New York, and report that 59% had a diagnosed psychiatric disorder (including anxiety 19%, depression 14%, OCD 12%, bipolar disorder 13%, psychosis 18%, impulse disorder 21%, personality disorder 8%, and 8% ASD). The overall prevalence of psychiatric disorder in the present sample is comparable, especially given that Tsiouris et al (2011) included a broader range of disorders. Tyrer et al (2009) used the Mini PAS-ADD to screen for psychiatric disorder among participants with aggressive behaviour recruited to a randomised controlled trial for aggressive challenging behaviour, and report that 58% met at least one threshold for 'likely psychiatric pathology' (including ASD) with 22% meeting the threshold for anxiety disorder, 15.1% for mania, 12.8% for psychotic disorder, 9.3% for depression and 9.3% for ASD. Holden and Gitlesen (2008), using the PAS-ADD Checklist, ascertained that, of their sample of adults with ID receiving care and with at least 'less demanding' challenging behaviour, 10.1% reached the threshold for organic condition, 24.4% reached the threshold for affective or neurotic disorder, and 18.5% reached the threshold for psychotic disorder. Whilst reported rates vary, most studies suggest that anxiety disorders predominate. The prevalence of ASD is higher in the present sample than population-based estimates, which report figures around 8-20% (Underwood et al, 2010), however, other authors have suggested co-occurrence of ASD and ID of 40% (Matson & Shoemaker, 2009). Numerous studies have reported an association between ASD and aggressive behaviour (e.g. Felce & Kerr, 2013; Tsiouris et al, 2011; McCarthy et al, 2010; Crocker et al, 2006; McClintock et al, 2003; Collacott, 1998b).

There were discrepancies between carer's knowledge of psychiatric diagnoses and potential mental health problems identified by the Mini PAS-ADD. This scale identified more cases of mental health problems (excluding ASD) with a different profile: depressive disorder was less common and anxiety disorder and OCD more common. Rates of the other mental health problems were more comparable. As the Mini PAS-ADD is a screening instrument, it may be anticipated that more cases are detected than would be diagnosed by a clinician. However, the Mini PAS-ADD has been shown to have good construct and concurrent validity (see Chapter 2). Furthermore, there were fewer cases of ASD identified by the Mini PAS-ADD compared to carer report. The Mini PAS-ADD requires a participant to meet the threshold score for all three subscales of ASD for it to be indicated. When the individual subscales are considered, the numbers of participants exhibiting autistic symptoms and those for whom a diagnosis was known by the carer are more comparable. This difference may therefore reflect a stricter definition of ASD for the Mini PAS-ADD than clinician's expert opinion. The Mini PAS-ADD data will be used in subsequent chapters as this has been validated as a reliable screen for psychiatric problems and rates represent current level of symptomatology (see Chapter 2). Using carer's knowledge may be less accurate as it may be open to bias, may reflect carer self-diagnosis or assumptions or may reflect an historic diagnosis where they are no longer symptoms.

Recruitment and Attrition

The reasons for the low recruitment rates are discussed in Appendix 17. Most relate to the field of research and longitudinal nature of the study and other authors have commented on the difficulties of recruiting and retaining adults with ID in research (Nicholson et al, 2012; Oliver-Africano et al, 2010; Cooper et al, 2009b; Lennox et al, 2005). Whilst the attrition rates appear high, they are largely comparable with other longitudinal studies in the field and are acceptable given the target population, length of follow-up, multiple data collection points and use of informants. For example, other longitudinal studies report attrition rates of over 27% and 30% in two years, with only one follow-up (Cooper et al, 2009a; Cooper et al, 2009b; Cooper et al, 2007; Smiley et al, 2007). The reasons for loss to follow-up are examined in detail in Appendix 17. Most commonly, loss to follow-up was because the carer had moved employment, this is particularly pertinent in the field of ID where there is high staff turnover in residential care (Hatton et al, 2001 Larson & Lakin, 1999; Mitchell & Braddock, 1994). Furthermore, in some cases it was impossible to find a mutually convenient time and location for the follow-up interview or the carer was too busy. Again, this is particularly relevant to the present field of research, as carer burden has been shown to be related to aggressive behaviour (e.g. Unwin & Deb, 2011, see discussion in Chapter 1) which may have precluded participation in follow-up interviews, despite efforts to accommodate the needs of participants and carers. This may have introduced bias to the sample at end-point. However, there were no differences in the characteristics of those who were lost to follow-up compared to those who completed the study, suggesting that the cohort who completed the study was comparable to those who entered the study.

Conclusions

An aim of the present chapter was to compare the study sample with a large, clinic sample of community-based adults with ID and aggressive behaviour to assess representativeness. A comprehensive literature search was undertaken to locate a recent paper that reported demographic data for such as sample, however, no such data could be located. Therefore, comparisons were made with a dated paper that included adults who were living in institutions as well as those living in the community (Sigafoos et al, 1994). This highlights a need for further research to profile the demographics of community-based adults with ID and aggressive behaviour, taking an epidemiological perspective. Whilst the present sample is not population-based, it does provide a novel summary of the profile of a relatively large clinic, community-based sample of adults with ID and aggressive behaviour. The sample is more representative of current trends as most people with ID now reside in the community rather than in institutions.

The demographic profile of present study sample is largely representative of a clinic sample of adults with ID and aggressive behaviour (Sigafoos et al, 1994). Similarly, the present sample is comparable with the eligible clinic population from which it was drawn. The results of this study may therefore be generalisable to other clinic populations with ID and aggressive behaviour. However, differences were observed when comparing the sample to all clients of the recruitment centres. Those who were eligible to take part tended to be younger. Similar discrepancies were observed when the demographic profile of the present study was compared to epidemiological studies. This finding compliments existing research that suggests aggressive behaviour is more common in younger adults. The proportion of males and those with ASD tended to be higher in the present sample compared to rates reported in population-based studies. This indicates that the present sample is not comparable to the wider ID population with such demographic variables potentially being associated with aggressive behaviour.

All the variables outlined in the present chapter have been implicated in the literature as having an association with aggressive behaviour, however, conflicting results have been reported meaning that the relationship is, as yet, unclear. Further prospective research is needed, looking at different types of aggressive behaviour to delineate any associations. These data were therefore collected to allow further analyses, presented in Chapter 5 to examine the relationships between demographic, health/medical, and behavioural variables and type and severity of aggressive behaviour.

CHAPTER 4: NATURAL HISTORY, TOPOGRAPHY AND TRAJECTORY OF AGGRESSIVE BEHAVIOUR AND RELATED OUTCOMES

Introduction

Epidemiological research has investigated the topography of aggressive behaviour, including breakdown of the rates of certain types of aggressive behaviour, although these tend to recruit population-based rather than clinic samples (e.g. Cooper et al, 2009a; Cooper et al, 2009b; Lowe et al, 2007a; Emerson et al, 2001a). Available studies of aggressive behaviour report verbal aggression as being most common (Tsiouris et al, 2011; Crocker et al, 2006). However, the majority of studies examine challenging behaviour (and therefore tend to study more severe behaviours, see discussion on terminology in Chapter 1) and suggest that physically aggressive behaviour is more common (Lowe et al, 2007a; Emerson et al, 2001a), often excluding verbal aggression from the study. Conversely, most studies report that aggressive or challenging behaviours are predominantly less severe, with only a minority presenting the most severe forms of behaviour (Lowe et al 2007a; Crocker et al, 2006). Despite this, less severe forms of behaviour can present management difficulties and may act as a barrier to social inclusion. For example, Lundström and colleagues (2011) found that screaming and shouting independently predicted use of physical restraint in Swedish group homes. Furthermore, recent studies of specialist inpatient units for aggressive behaviour have reported that around 50-60% of all incidents are verbally aggressive (Drieschner et al, 2013; Tenneij & Koot, 2008).

Whilst some research considers specific types of aggressive behaviour in isolation, topographical research has suggested that aggressive behaviours tend to overlap (Cooper et al, 2009b) with most individuals displaying multiple forms of behaviour (Tsiouris et al, 2011; Lowe et al, 2007a; Crocker et al, 2006; Borthwick-Duffy, 1994). Furthermore, those who exhibit aggressive behaviour may also exhibit other types of behaviour such as hyperactivity or social withdrawal (Oliver et al, 2012; Richards et al, 2012; Cooper et al 2009a; Cooper et al, 2009b; Harris 1993). However, the pattern of inter-relations remains unclear with limited research investigating in detail, the relationships between types of aggressive behaviour (including severity) and other behaviours. There is currently scant literature that describes the topography of aggressive behaviour of a large clinic, community-based sample, such a description can help inform service provision and planning.

Aggressive behaviour has been reported to be associated with reduced quality of life and negative outcomes for carers (e.g. Rose et al, 2013a; Rose et al, 2013b; Rose, 2011, see Chapter 1). However, the pattern of this association remains unclear with little research conducted longitudinally involving large clinic samples. Understanding the relationship between topography of aggressive behaviour and other outcomes for the person and people around them is important to ensure services meet the needs of patients, families and carers. Moreover, the author is not aware of any research that examines the prospective trajectory of other holistic variables in a cohort with aggressive behaviour. Such variables may demonstrate a different pattern over time.

Previous research suggests that problem behaviours, including aggressive behaviour tend to emerge in childhood (Emerson & Einfeld, 2011) and persist over time (e.g. Thompson & Reid, 2002; Emerson et al, 2001b; Kiernan & Alborz, 1996; Reid et al, 1984). However, contemporary research is lacking to corroborate this assertion (Emerson & Einfeld, 2011; Cooper et al, 2009a; 2009b). Currently, little is known about the development, natural history and trajectory of aggressive behaviour over time (Emerson & Einfeld, 2011; Horowitz et al, 2011; Totsika & Hastings, 2009; Benson & Brooks, 2008). Persistence rates of around 70-80% over 2-11 year periods have been reported (Cooper et al, 2009b; Totsika et al, 2008; Kiernan & Alborz, 1996). However, these rates vary according to time period and types of behaviour studied and imply that, for a proportion of individuals, aggressive behaviours may abate. However, further research is needed to clarify the manifestation of aggressive behaviour over time, especially investigating severity as well as continued prevalence.

When considering change in behaviour over time, it may be important to consider clinically reliable and significant change, as well as statistically significant change. Jacobson and Truax (1991) argue for the importance of examining clinically significant and reliable change, as well as effect sizes and statistical significance. This is because effect sizes may be independent of clinical significance in some cases, with small, non-significant effects being clinically important. Jacobson and Truax (1991) propose a method for calculating reliable change: the change that has occurred over and above the variability in change scores as a result of using an imprecise measuring tool. This is particularly useful in the field of Psychology where direct measures of constructs are often impossible and therefore measurement bias may be introduced by using assessment scales approximating the construct under investigation.

This chapter investigates the retrospective history and prospective trajectory of aggressive behaviour. As all the participants are in contact with services for help managing behaviour, the analyses of the prospective data will establish the extent to which aggressive behaviours persist, despite this contact with services. The trajectories of other variables are also investigated to examine the associated pattern of other problem behaviours, quality of life and outcomes for carers. Existing research regularly fails to examine these variables, instead focussing solely on severity or persistence of aggressive behaviour. Participants whose behaviour demonstrated a clinically significant and reliable change are also identified and contrasted with those whose behaviour remained stable or worsened, to find out whether such individuals differ in demographic profile. As few studies have documented the cross-sectional profile of aggressive behaviour amongst a community-based clinic sample of adults with ID, the profile of aggressive behaviour of the cohort at T1 is described along with the extent to which sub-types of behaviour interrelate. Furthermore, the relationships between severity of aggressive behaviour, quality of life and outcomes for carers are investigated.

Methods

The topography of aggressive behaviour at T1 was analysed using descriptive statistics to summarise MOAS and ABC-I scores. Topography and relationships with other problem behaviour, quality of life and outcomes for carers were further investigated using Spearman's correlation analyses. In addition, A Venn diagram sought to pictorially represent the inter-relations between types of aggressive behaviour using data from MOAS subscales, coded as behaviour present or absent.

Retrospective data pertaining to the history of aggressive behaviour were analysed by examining mean age of onset and mean age when medical help was first sought. Prospective follow-up data were analysed using one way repeated measures ANOVAs or Friedman's ANOVAs to investigate the trajectory of severity of aggressive behaviour (MOAS and ABC-I), severity of other problem behaviours (other subscales of the ABC), quality of life, carer's concerns, and for family carers, uplift and burden over the 12-month follow-up. Planned comparisons (repeated measures t-tests or Wilcoxon signed-rank tests) investigated changes during the periods T1 to T2 and T2 to T3. The alpha level for these analyses was adjusted using Bonferroni's correction, and was therefore set at .025 (original alpha=.05, adjusted for two analyses).

Participants were categorised based on whether their ABC-I scores demonstrated clinically significant change and reliable change from T1 to T3. ABC-I was selected as it approximated the normal distribution and normative data were available to allow the calculation of clinically significant change. As suggested by Jacobson and Truax (1991), a cut off for clinically significant change was calculated by summing the mean of the sample (a clinical cohort) and the normative mean (taken from Aman et al, 1995; n=907 community-based adults with ID) and dividing by two. The cut-off score of 12.98 was then used to categorise participants as demonstrating a clinically significant change, in that they moved from being closer to the mean of the clinic sample to that of the normative sample (a T3 ABC-I score of >13). Reliable change was also calculated following the method presented by Jacobson and Truax (1991) to determine whether the change observed in ABC-I score from T1 to T3 was over and above an estimate of measurement error. Participants who demonstrated both clinically significant and reliable change were identified and their demographic profile compared using Pearson's chi-square tests.

Topography of Aggressive Behaviour at T1

Prevalence of Types of Aggressive Behaviour at T1

Table 7 provides summary statistics for the MOAS at T1, including the prevalence of each type of aggressive behaviour and prevalence of subtypes. Verbal aggression was the most common form of aggressive behaviour and most participants displayed aggressive behaviour in milder forms. Mean and median scores are presented as, whilst the MOAS subscale scores are not normally distributed, the median score is zero in some cases, therefore, the mean scores are also presented to provide further information.

Severity of Aggressive Behaviour at T1

The median weighted MOAS score for the sample at T1 was 9 (IQR 13, range 0-26, n=99, data were not available for all participants). The mean score on the ABC-I at T1 was 14.82 (SD 9.14; range 1-39, n=96, data were not available for all participants).

Table 7: Descriptives for MOAS at T1 (N=99[a])

MOAS subscale	**Median score (IQR)** **Mean score (SD)**	**Range**	**Example behaviours (weighted MOAS score)**	**N (%)**
Verbal aggression	1 (2) 1.64 (1.34)	0-4	Any (1-4)	76 (76.77)
			Makes loud noises, shouts angrily (1)	33 (33.33)
			Yells mild personal insults (2)	10 (10.10)
			Curses viciously, uses foul language in anger, makes moderate threats to others or self (3)	23 (23.23)
			Clear threats of violence toward others or self (4)	10 (10.10)
Physical aggression against objects	2 (4) 2.04 (2.08)	0-6	Any (2-8)	54 (54.55)
			Slams doors, scatters clothing, makes a mess (2)	14 (14.14)
			Throws objects down, kicks furniture without breaking it, marks the wall (4)	33 (33.33)
			Breaks objects, smashes windows (6)	7 (7.07)
			Sets fires, throws objects dangerously (8)	0
Physical aggression against self	0 (6) 2.52 (3.50)	0-12	Any (3-12)	42 (42.42)
			Picks or scratches skin, hits self, pulls hair (with no or minor injury only) (3)	17 (17.17)
			Bangs head, hits fist onto objects, throws self onto floor or into objects (hurts self without serious injury) (6)	12 (12.12)
			Small cuts or bruises and minor burns (9)	10 (10.10)
			Mutilates self, causes deep cuts, bites that bleed, internal injury, fracture, loss of consciousness, loss of teeth (12)	3 (3.03)
Physical aggression against others	0 (0-8) 3.39 (4.55)	0-12	Any (4-16)	41 (41.41)
			Threatening gestures, swings at people, grabs at clothes (4)	12 (12.12)
			Strikes, kicks, pushes, pulls hairs, with no injury to others (8)	15 (15.15)
			Attacks others causing mild-moderate physical injury (bruises, sprains, welts) (12)	14 (14.14)
			Causes severe physical injury (broken bones, deep lacerations, internal injury) (16)	0

[a] Data not available for all participants.

<u>Inter-relations between Types of Aggressive Behaviour, Problem Behaviours, Quality of Life and Outcomes for Carers at T1</u>

The majority of participants exhibited more than one type of behaviour (n=65, 65.66%). Twenty (20.20%) showed two types of aggressive behaviour, 33 (33.33%) three types and 12 (12.12%) showed all four types. The mean number of types of aggressive behaviour exhibited by the participants was 2.15 (SD=1.18).

Table 8 presents a correlation matrix for the MOAS subscale scores. All three types of outwardly-directed aggression were significantly positively correlated. The correlation coefficients of .24-.35 indicate a medium effect between these variables (Field, 2005), however, SIB was not related. Figure 5 shows the inter-relations between presence of types of aggressive behaviour. Few participants showed property destruction and SIB in isolation and all those who showed physical aggression to others also exhibited other types of aggressive behaviour. Not represented on the diagram due to lack of space are those who showed verbal aggression and self injury (n=5, 5.05%) and property destruction and physical aggression to others (n=1, 1.01%).

Table 8: Correlations between MOAS subscale scores at T1 (r_s values; N=99[a])

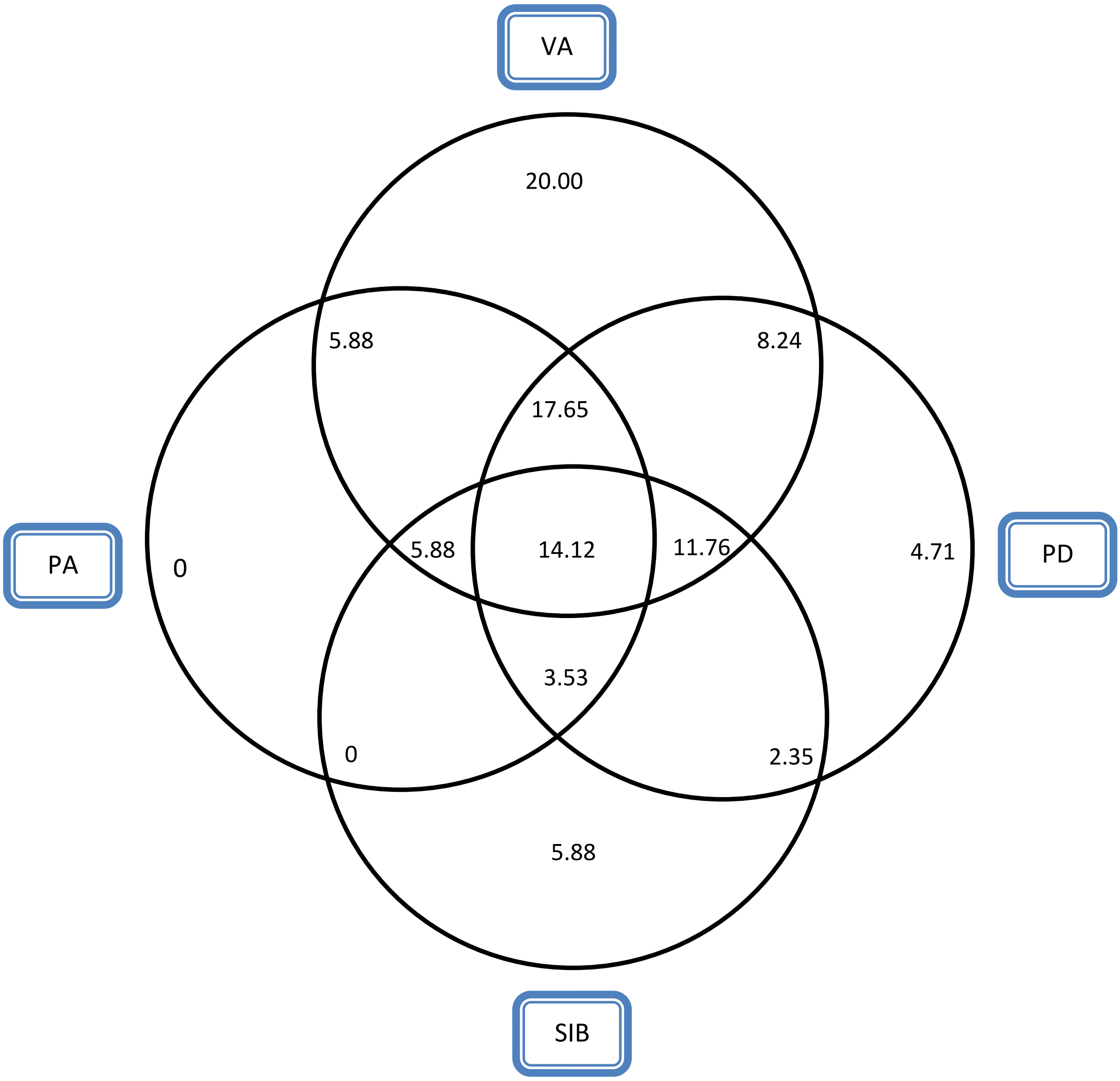
MOAS subscale	Physical aggression against objects	Physical aggression against self	Physical aggression against other people
Verbal aggression	.24*	-.11	.33**
Physical aggression against objects	-	.15	.35**
Physical aggression against self	-	-	.13
Physical aggression against other people	-	-	-

*Significant correlation at p<0.05 level.
**Significant correlation at p<0.01 level.
[a]Data not available for all participants.

The relationships between severity of aggressive behaviour, severity of other problem behaviour, quality of life and outcomes for carers were also investigated (see Appendix 19). ABC-I scores were positively correlated with all other ABC subscale scores (p<0.01). MOAS scores were correlated with all other variables apart from ABC-Inappropriate Speech. ABC-I scores were correlated with all other measures apart from quality of life. The strongest relationship for quality of life was with ABC-lethargy/social withdrawal (r_s=-.42, p<.0001). The strongest relationships with outcomes for family carers, namely uplift and burden, were both measures of severity of aggressive behaviour (Uplift: r_s=-

.32, p=.04 for MOAS, r_s=-.50, p=.001 for ABC-I; Burden: r_s=.50, p=.001 for MOAS, r_s=.60, p<.001 for ABC-I). Carer's concern was related to all other variables with a moderate effect size.

Figure 5: Inter-relations between presence (%) of types of aggressive behaviour at T1 (N=85)



VA: Verbal aggression
PD: Physical aggression against objects
PA: Physical aggression against others
SIB: Physical aggression against the self

Natural History of Aggressive Behaviour (Retrospective Data)

The majority of carers did not know how old the participant was when the behaviour first manifested (n=61) and stated that it was before they started providing care (n=58). No paid carers were able to provide an age. Most family carers were able to provide an age estimate (n=43). The majority of aggressive behaviours emerged in childhood and adolescence (0-12 years, n=21, 48.84%; 13-16 years, n=11, 25.58%). Age of onset was in young adulthood for five participants (17-21 years, 11.63%), and during adulthood for six individuals (22+ years, 13.95%). Thirty-nine family carers were able to provide a specific age when the behaviour first emerged; the mean age was 13.16 years (SD 10.31, range 1.4-44). Mean time since onset was therefore 15.27 years (SD 8.65, range 1-43 years).

Thirty-eight carers could recall the age when medical help was first sought for the aggressive behaviours. The mean age of the participants was 15.8 years (SD=10.37, range 1.5-44 years). Therefore, participants had potentially been in receipt of medical help for a mean of 12.59 years (SD 9.68, range 1-42 years). Forty carers could provide an age estimate rather than a specific age. For the majority, medical help was sought in childhood (n=14, 35%) and adolescence (n=13, 32.5%).

Trajectory of Aggressive Behaviour and Related Outcomes (Prospective Follow-up Data)

Severity of Aggressive Behaviour (ABC-I and Weighted MOAS)

Figures 6 and 7 summarise the scores on each measure of severity of aggression at each time point. Across the whole group, both measures of severity of aggression significantly reduced over the follow-up period (T1 mean=15.74, SD 9.97; T2 mean=12.36, SD 8.88; T3 mean=12.38, SD=8.72; F(2, 104)=7.57, p=.001, n=53 for ABC-I; T1 median=10, IQR 14; T2 median=6, IQR 6; T3 median=6, IQR 6; $X^2(2)=9.21$, p=.009, n=61 for MOAS). Planned comparisons revealed a significant reduction in severity of aggression scores during the period T1 to T2 (t(52)=3.195, p=.002 for ABC-I; Z=-2.54, p=.011, n=61 for MOAS). However, there were no significant changes in scores for the periods T2 to T3.

Other Problem Behaviours (ABC Subscale Scores)

Significant reductions in scores over the follow-up period were identified for some of the subscales of the ABC. Severity of lethargy/social withdrawal significantly reduced (T1 median=4.00, IQR 9.00; T2 median=3.00, IQR 7.00; T3 median=2.00, IQR 8.00; $X^2(2)=10.15$, p=.006, n=53), as did hyperactivity/non-compliance (T1 median=11.00, IQR 14.00; T2 median=7.00, IQR 11; T3 median=6.00, IQR 8.00; $X^2(2)=13.30$, p=.001, n=53). Planned comparisons revealed a significant change in score during the period T1 to T2 only (Z=-2.26, p=.009, n=53 for lethargy/social withdrawal; Z=-3.48, p=.001, n=53 for hyperactivity/non-compliance). However, stereotypic behaviour and inappropriate speech both remained stable (T1 median=3.00, IQR 7.00; T2 median=2.00, IQR 6.00; T3 median=2.00, IQR 6.00; T1 median=2.00, IQR 5.00; T2 median=1.00, IQR 5.00; T3 median=1.00, IQR 4.00 respectively).

Quality of Life

Quality of life scores remained stable over time (T1 mean=19.34, SD 5.79; T2 mean=20.36, SD 5.38; T3 mean=20.51, SD 4.63; F(2, 120)=2.67, p=.07, n=61).

Carer's Concerns

Carer's concerns significantly reduced over time ($X^2(2)=13.12$, p=.001, n=61). Planned comparisons revealed a significant reduction from T1 to T2 (T1 median=11.00, IQR 8.00; T2 median=9.00, IQR 7.00; Z=-2.55, p=.011, n=61) and from T2 to T3 (T3 median=7.00 IQR 7.00; Z=-2.91, p=.004, n=61).

Family Carer's Uplift and Burden

Data from 23 family carers were available at all time points. Uplift remained stable across the time points (T1 median=15.00, IQR 5.00; T2 median=16.00, IQR 5.00; T3 median=15.00, IQR 5.00; $X^2(2)=1.85$, p=.40). Similarly, burden scores remained stable over time (T1 mean=33.30, SD 8.51; T2 mean=30.17, SD 9.96; T3 mean=30.35, SD 10.03; F(1.21, 26.56)=3.65, p=.06).

Figure 6: Median ABC-I scores at each time point (n=53)

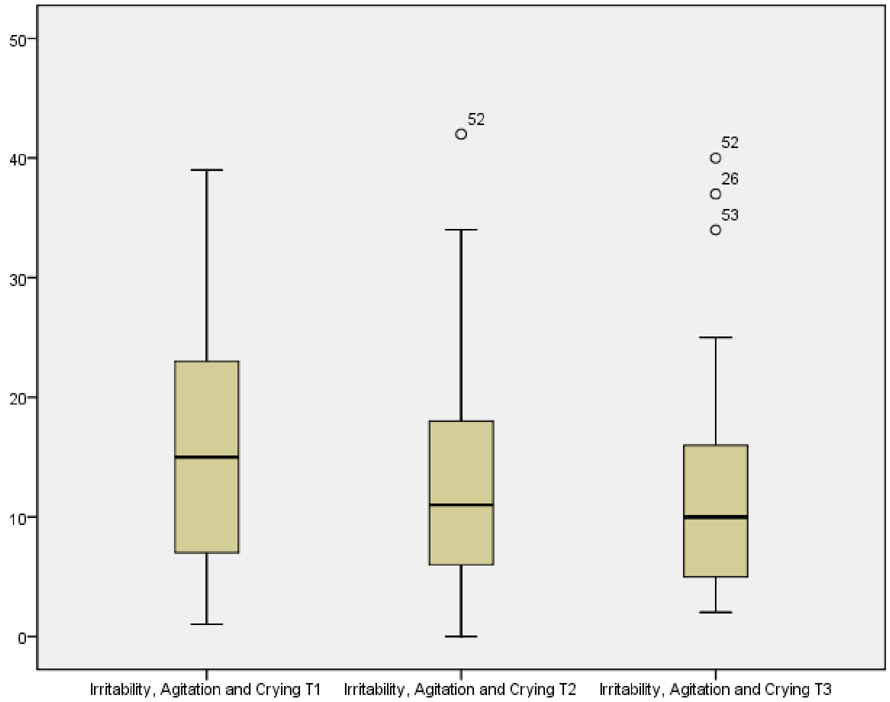
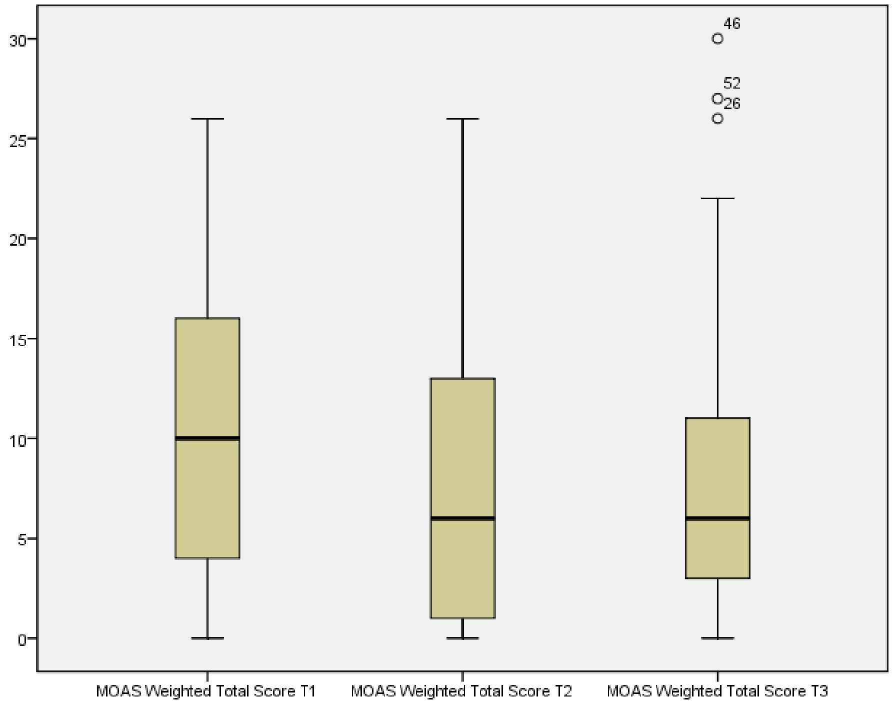


Figure 7: Median weighted MOAS scores at each time point (n=61)



Clinically Significant and Reliable Change

At T3, 35 (62.50%) participants out of the 56 followed-up and with data on the ABC-I were below the threshold for clinically significant change. However, of these 35 individuals, only 12 (21.43%) had T1 scores higher than the threshold, meaning that 12 participants moved from severity of aggression more akin to a clinic population to severity more akin to the general ID population.

Thirty-three (58.93%) participants demonstrated a reliable change in ABC-I score from T1 to T3: the behaviour of seven (12.50%) became more severe, meaning 26 (46.43%) participants demonstrated a reliable improvement in severity of aggression. Ten (17.24%) participants showed a clinically significant and reliable change, moving from a clinically-relevant ABC-I score to one that was closer to the normal mean score for the population. Chi-squared analyses revealed no significant differences in the demographic profiles of those who demonstrated a clinically significant or reliable change, and those who demonstrated no change or worsened.

Discussion

The present chapter sought to summarise the past, current and prospective topography of aggressive behaviour and related outcomes. Aggressive behaviour was generally long-standing, having first emerged in childhood and adolescence. At T1, the behaviour of the cohort was generally in the mild to moderate range with verbal aggression most common, however, the majority of participants exhibited multiple forms of aggressive behaviour and the severity of behaviours were all interrelated apart from SIB. Similarly, severity of aggressive behaviour was related to severity of other problem behaviour and family carer uplift and burden. Quality of life was not related to severity of aggressive behaviour. Aggressive behaviour improved over the 12-month follow-up with 17% of participants demonstrating a clinically significant and reliable improvement. Lethargy/social withdrawal, hyperactivity/non-compliance and carer’s concerns also improved. Quality of life and family carer uplift and burden remained stable.

Topography of Aggressive Behaviour at T1

As with the present study, Crocker and colleagues (2006) reported MOAS scores skewed towards the lower end of each subscale among 3,165 adults with ID receiving social care services in Canada. The present sample were all in contact with health services for the management of aggressive behaviour suggesting that, whilst less severe aggressive behaviour is more common, it may still require intervention and help from services. Recent studies of ID inpatient units for aggressive behaviour indicate that over half of recorded aggressive incidents are verbal aggression, often considered as less severe (Drieschner et al, 2013; Tenneij & Koot, 2008).

Few studies are available that report severity of aggressive behaviour using standardised, validated scales amongst a clinic sample of adults with ID. One of the few existing studies by Rojahn and colleagues (2011) reported a mean score of 16.3 (SD 10.1) on the ABC-I for 118 participants recruited from specialist psychiatric outpatient clinics in Northern Virginia providing behavioural and psychiatric consultation and treatment. The sample mean ABC-I score is slightly lower at 14.82 (SD 9.14), however, comparison of the means from each study revealed no significant differences (p=.87). In developing the ABC, Aman and colleagues (1995) presented normative data, derived from 1,024 adults with ID residing in group homes in Midwestern USA. They report mean ABC-I scores ranging from 9.92 to 11.87 across levels of ID. As would be expected, the present sample exhibited more severe aggressive behaviour. Similarly, Myrbakk and von Tetzchner (2008a) reported a lower mean ABC-I score of 5.6 (SD=8.6, range=0-40) across a community-based, non-clinical sample of adolescents and adults with ID.

Aggressive behaviour at T1 demonstrated a similar profile to that reported in some previous research (see Table 9). In most cases, verbal aggression was most common with more comparable rates for the other three types of aggressive behaviour. However, property destruction was relatively more common in the present sample. This may relate to the high incidence of co-morbid ASD (24%

compared to 9.7% in Tsiouris et al, 2011) as ASD has been reported to be associated with higher rates of property destruction (Tsiouris et al, 2011). It may also be explained by differences in sampling as this study recruited a clinic sample in contact with services specifically for aggressive behaviour and therefore, clinical input may be more commonly sought for property destruction.

Table 9: Prevalence rates of types of aggressive behaviour (%)

<table>
<tr><th>Author
Year</th><th>Verbal aggression</th><th>Property destruction</th><th>Physical aggression to others</th><th>SIB</th></tr>
<tr><td>Present Study</td><td>77.77</td><td>54.55</td><td>41.41</td><td>42.42</td></tr>
<tr><td>Chaib & Crocker 2013</td><td>64.1</td><td>47.1</td><td>45.8</td><td>24.3</td></tr>
<tr><td>Lundqvist 2013</td><td>-</td><td colspan="2">34.4</td><td>39.9</td></tr>
<tr><td>Tsakanikos et al 2011</td><td>-</td><td>22.7</td><td>30.8</td><td>13.9</td></tr>
<tr><td>Tsiouris et al 2011</td><td>72</td><td>46</td><td>58</td><td>40</td></tr>
<tr><td>Hove & Havik 2008</td><td>8.3</td><td>4.7</td><td>10.5</td><td>5.4</td></tr>
<tr><td>Jones et al 2008</td><td>7.5</td><td>3.0</td><td>6.3</td><td>4.9</td></tr>
<tr><td>Lowe et al 2007a</td><td>-</td><td>57</td><td>82</td><td>57</td></tr>
<tr><td>Crocker et al 2006</td><td>37.6</td><td>24.0</td><td>24.4</td><td>24.4</td></tr>
<tr><td>Emerson et al 2001a</td><td>-</td><td>33</td><td>58</td><td>28</td></tr>
<tr><td>Qureshi & Alborz 1992</td><td>-</td><td>54</td><td>62</td><td>46</td></tr>
</table>

Different patterns for prevalence of aggressive behaviour have been reported elsewhere. For example, studies have reported physical aggression to others to be most common; however, these focus on challenging behaviour and do not include verbal aggression (Lowe et al, 2007a; Emerson et al, 2001a). One study reported physical aggression to others to be more prevalent than verbal aggression among community-based adults with ID (Hove & Havik, 2008). Increased prevalence of physical aggression towards others reported in some studies, compared to this study, may be due to sampling differences and definitions used. For example, some have restrictions relating to severity of behaviour or use the DC-LD (RCPsych, 2001) definition, which excludes problem behaviour due to an underlying mental health problem. To the author's knowledge, the present study is the first to report the prevalence of each of the four types of aggressive behaviour amongst a large community-based clinic sample of adults with aggressive behaviour in the UK.

There was a high degree of overlap between the types of aggressive behaviour with only 26 participants exhibiting a single type of aggressive behaviour, most commonly, verbal aggression. All those who displayed physical aggression towards others showed multiple behaviours. Crocker and colleagues (2006) found that 62% of those who displayed aggressive behaviour displayed two or more types of aggressive behaviour. Similarly, Cooper and colleagues (2009b) reported that 51.8% of their sample exhibited two or more types of outwardly-directed aggressive behaviour. In the present sample 49.49% exhibited outwardly-directed aggression alone and only 5.05% showed SIB alone. Similar findings have also been reported in studies of inpatient and community residential facilities (Taylor et al, 2011; Tsiouris et al, 2011; Tenneij & Koot, 2008).

Severity of all three types of outwardly-directed aggressive behaviour was significantly, positively correlated. Crocker and colleagues (2006) also report that severity all types of aggressive behaviour were significantly associated with each other, with verbal, physical to others and property destruction, yielding a large effect (r_s=.53-.59) whereas SIB produced a smaller effect (r_s=.26-.38). The associations in the present study yielded smaller effect sizes and SIB was found not to be associated. This may be explained by the different time periods studied (week preceding interview versus a 12-month period). More recently, Taylor and colleagues (2011) reported no significant correlations between severity of SIB and severity of physical aggression to others or property, however, severity of SIB was associated with severity of stereotyped behaviour. In the present study, severity of aggressive behaviour was significantly associated with severity of all other problem behaviours.

Harris (1993) also reported a high co-occurrence of aggressive, ritualistic, stereotypical and withdrawn behaviour. Presence of aggressive behaviour has been linked to presence of ADHD in adults with ID (comprising symptoms of inattentiveness, hyperactivity and impulsiveness) (Cooper et al, 2009a; 2009b), high frequency repetitive or ritualistic behaviours have been associated with increased prevalence and severity of aggressive behaviours in children with severe ID (Oliver et al, 2012) and repetitiveness and impulsivity have been linked to aggressive behaviour in those with genetic syndromes with ID (Arron et al, 2011).

Some studies of aggressive behaviour focus on a specific type of behaviour, with many addressing either outwardly-directed or SIB (e.g. Cooper et al 2009a; 2009b). There is some evidence to suggest that severity of SIB may be independent of severity of outwardly-directed aggressive behaviour, although the very high rates of co-occurrence support the study of aggressive behaviour as encompassing the four types included in this study. Crocker and colleagues (2007) sought to develop profiles of aggressive behaviour in adults with mild or moderate ID and the topography of behaviour of the present cohort compliments these profiles.

Natural History of Aggressive Behaviour

Aggressive behaviours tended to emerge in childhood, around the age of 13 years. This could be when behaviours were first exhibited or when behaviours were first noted by family carers as the child became physically bigger and behaviours became more challenging. There has been very little research on the development of aggressive behaviour (Benson & Brooks, 2008); however, this finding compliments the limited existing retrospective research which suggests that problem behaviours are likely to emerge in childhood (Emerson & Einfeld, 2011). Available studies tend to focus on severe challenging behaviour and, more specifically, SIB, quoting a young age of onset (Richman & Lindauer, 2005; Schneider et al, 1996). For example, a retrospective study of severe SIB (managed by protective devices) reported the mean age of onset of 7 years (Murphy et al, 1993). Other studies have reported much earlier ages of onset for SIB, with a recent systematic review concluding age of onset tended to be before age 25 months, however, these are based on small samples (Furniss & Biswas, 2012). As only family carers were able to recall age of onset, it may be that those remaining with family carers tended to exhibit less severe aggressive behaviour with later age of onset, whilst those with earlier age of onset moved into residential care, possibly due to placement breakdown due to aggression; this could represent selection bias. Indeed, aggressive behaviour has been linked to increased placement breakdown (Emerson, 2002). Furthermore, it has been hypothesised that SIB has an endogenous cause (Furniss & Biswas, 2012) and therefore may be prevalent from an early age, whereas other types of aggressive behaviour may be learned (Oliver, 2005) and therefore emerge later (see discussion on aetiology in Chapter 1).

The average age where medical help was first sought for aggressive behaviour was around 16 years, suggesting that around three years after behaviours were first noted, carers felt compelled to access support for the behaviour. Powell and colleagues (2007) suggested that aggressive behaviour in young children with developmental delays was under identified and inadequately addressed in early intervention programmes and these data indicate a substantial time lag between age of emergence and help-seeking. The only comparable existing study, again investigating more severe challenging behaviour, indicated that of 29 individuals identified by services as ‘most challenging’, 27 had been admitted to some form of institutional care, with the average age of admittance being 9.6 years. Again, this age is lower than the age for when medical help was first sought, which may suggest that more severe behaviours tend to emerge and require intervention at an earlier age. Furthermore, as with age of onset, selection bias may be present because only family carers were able to provide these data. To the author’s knowledge, there are no retrospective studies that investigate the mean age of onset for aggressive behaviour in an adult ID clinic population who continue to exhibit aggressive behaviour requiring contact with community health services. Similarly, there are no known prospective studies that have followed a child cohort with aggressive behaviour, from age of onset into adulthood.

Most paid carers (95%) stated that aggressive behaviour was present when they first started caring and remained persistent throughout the time they had known the participant. As most carers had known the participant for at least five years, it can be asserted that aggressive behaviours in the sample were generally long-standing. Furthermore, mean time since age of onset was 15.27 years. This finding is in line with what is generally assumed in the literature: that aggressive behaviours are persistent (Kiernan & Alborz, 1996). However, aggressive behaviour may not have been constant throughout this time and fluctuations in severity may have occurred. Cooper and colleagues (2009a; 2009b) suggest that aggressive behaviours may be episodic (‘relapsing-remitting problems’) and warn against ‘therapeutic nihilism’ whereby aggressive behaviours are assumed to be persistent over time, despite therapeutic efforts and management strategies.

Trajectory of Aggressive Behaviour and Related Outcome Measures

Few studies have explored the trajectory of aggressive behaviour and associated outcomes with multiple time points. Most studies examine the persistence of (more severe) challenging behaviour or SIB over long periods of time, as opposed to fluctuations in the severity of aggressive behaviours, resulting in little existing literature with which to compare the present results. For example, Taylor and colleagues (2011) report high levels of chronicity for SIB, with 84% of their sample continuing to self-injure after 20 years with no significant changes in severity, others have reported persistence of 62% for SIB over a two year period (Cooper et al, 2009a). One study investigating severity of behaviours over time reported a correlation coefficient of around 0.4 for overall severity of problem behaviour (not including aggressive behaviour), separated by 12 years (Murphy et al, 2005).

In the present study, severity of aggressive behaviour significantly improved over the follow-up period. Planned comparisons revealed the improvement occurred during the first six-month follow-up period with no further change during T2 to T3. Significant reductions in severity were also observed for two of the other four behaviours measured by the ABC, namely lethargy/social withdrawal and hyperactivity, with improvement T1 to T2. Stereotypic behaviour and inappropriate speech both remained stable throughout the follow-up period. This may be because they are associated with more enduring conditions and are therefore less prone to fluctuations over time. For example, stereotypic behaviour and inappropriate speech are considered core features of ASD (Wing, 1996) and such symptoms tend to be persistent in people with ASD (Matson & Shoemaker, 2009).

Previous research has demonstrated a link between aggressive behaviour and quality of life (Murphy, 2009; Myrbakk & von Tetzchner, 2008a), however, in the present study, quality of life did not show the same trajectory as severity of aggression, with quality of life scores remaining stable throughout. Quality of life was measured largely in relation to activities and relationships with others, therefore a longer duration may be required for the impact of a reduction of aggressive behaviour to be noted with changes in quality of life demonstrating a time lag after improvements in aggressive behaviour. In terms of the cross-sectional data, quality of life scores demonstrated the strongest correlation with lethargy and social withdrawal, only a small effect was observed for MOAS scores and no effect was observed for ABC-I scores, suggesting that quality of life may be more closely related to other problem behaviours.

Outcomes for carers demonstrated some changes, with a significant reduction in carer’s concerns. However, family carer uplift and burden remained stable throughout. Median family carer uplift scores were 15-16 out of a possible 16, indicating that uplift was high and therefore may have been subject to ceiling effects. Research has demonstrated that carer’s uplift is independent of various characteristics of adults with ID and only moderately associated with severity of aggression (Unwin &

Deb, 2011). The experience of caring for a family member with ID and aggressive behaviour has been described as an uplifting, satisfying and positive experience by carers, despite its challenges (Young & Koritsas, 2012; Unwin & Deb, 2011; Jokinen & Brown, 2005; Maes et al, 2003). The majority of parents of individuals with ID experience high levels of satisfaction and quality of life (Caples & Sweeney, 2010; Minnes et al, 2007). Furthermore, carers of adults with ID experience rewards, gratifications and a sense of personal satisfaction as part of the care giving role (Yoong & Koritsas, 2012; Grant et al, 1998). As the aggressive behaviour was generally long-standing, carers may have habituated to the behaviour and therefore demonstrate little change in uplift or burden. Furthermore, uplift and burden were only measured in family carers and were not measured solely in relation to aggressive behaviour, but rather, the measures included broader aspects of caring that would not be expected to change when considering the life-long condition of ID. A recent trial of applied behaviour analysis for challenging behaviour reported improvements in both uplift and burden in both arms of the trial which were more pronounced after 24 months, suggesting perhaps a longer follow-up is required (Hassiotis et al, 2012). The positive result for both arms may indicate a 'therapeutic effect' of being part of the trial or may suggest that standard support offered by CLDTs is effective in alleviating carer burden and may explain why no changes were observed in the present sample. It is encouraging that carer's concerns reduced over time, this may reflect the reduction in aggressive behaviour or the value of support received from specialist services.

Clinically Significant and Reliable Change

Twenty-one per cent of participants demonstrated a clinically significant improvement and 46% demonstrated a reliable improvement in severity of aggression over the 12-month follow-up. There were no differences in the demographic profile of those who demonstrated clinically significant or reliable change. Other longitudinal studies have also reported few differences among those who improve or deteriorate (Totsika et al, 2008). This finding is encouraging and may indicate that interventions were effective for some. It may also indicate that personal, stable factors are not informative about future aggressive behaviour. Some of the improvement observed across the group may have been due to regression to the mean. However, there was no eligibility stipulation on severity of aggression and no subgroup analyses were performed for those with more severe aggression, all elements which can inflate the effect of regression to the mean (Barnett et al, 2005). A scatter plot of change from T1 to T3 plotted against T1 scores did not reveal any significant regression to the mean effects (Barnett et al, 2005) and an estimate of the regression to the mean (following methods outlined by Wilhite, 2013) indicated that the reduction in ABC-I scores exceeded the likely regression to the mean.

Observer effects may also account for some of the improvement observed across the group. Participation in the study may have given carers the opportunity to reflect on their situation and the aggressive behaviour of the person they care for, especially given the content of the interview which asked carers to identify triggers. Carers may have identified previously unknown triggers during the first interview and implemented techniques to reduce the effect of such triggers ahead of the second interview. Participation in the interviews may also have been a cathartic experience for carers therefore improving their perception of and resilience to the behaviour by T2, this is especially pertinent as all outcome measures were carer reported. However, it is of note that such processes may only have had an effect from the first interview, as behaviour did not continue to demonstrate improvements during the second six month follow-up period. The relatively long six month interval between assessments and use of objective assessment scales may have reduced the potential of such effects.

Further research is needed to investigate the effects of interventions, especially given the often complex suite of interventions used to manage aggressive behaviour. However, the findings may indicate that for some, aggressive behaviour is naturally periodic, fluctuating in severity over time. A wide variety of factors may relate to fluctuations in severity such as life events, time of year, co-morbid disorders or health conditions and environmental factors. Therefore, the following chapters will seek to investigate such variables over time.

Jacobson & Truax (1991) comment on a potential limitation of their method: operationalizing clinical significance in terms of a recovery to ‘normal’ functioning is problematic for some conditions where a return to ‘normal’ functioning would exceed the expectations of clinicians. This may be relevant here, as small fluctuations in aggressive behaviour may be of significance, leading to improved outcomes for the person and their carer. No limits were placed on severity of aggressive behaviour of the cohort, therefore most exhibited milder forms of aggressive behaviour limiting the opportunity for clinically significant change, which requires a change of two SDs or more in the direction of functionality. Analysis of the trajectory of aggressive behaviour over time indicates statistically significant results but with relatively small effects with the change in mean ABC-I score across the sample being 3.36, therefore, clinically significant changes in this population may represent relatively small changes on outcome measures.

Conclusions

This chapter sought to explore the cross-sectional topography, retrospective natural history and prospective 12-month trajectory of aggressive behaviour across the whole cohort. In-depth analyses of longitudinal data such as these are unique in the study of aggressive behaviour in adults with ID, especially with multiple prospective data collection points over the short-term and which consider a range of outcomes.

Aggressive behaviour amongst the sample tended to be mild to moderately severe. Knowing the breakdown of types of aggressive behaviour as well as the severity of aggressive behaviour amongst a clinic sample may help inform future service planning and delivery. As all participants were in receipt of specialist services, it is suggested that even mild aggressive behaviour, including verbal aggression, may require intervention. However, the aggressive behaviour of the cohort was more severe than population-based estimates. The average scores for aggressive behaviour across the sample may therefore provide an indication of clinically significant aggressive behaviour. These scores could form an initial step towards assigning clinical cut-offs for the scales used. Furthermore, sample size and power calculations for future research, especially clinical trials may be informed by the data, including an indication of effect size for change over time. This is particularly important considering the persistence of aggressive behaviour, meaning that even small changes may be important but may be missed in small sample sizes. Until now, there were little data, derived from community-based, clinic samples in the UK on which to base these estimates.

As with previous studies, the majority of participants displayed multiple forms of aggressive behaviour. Indeed, all participants who exhibited physical aggression to others also displayed other forms of potentially less severe aggressive behaviour. This may suggest an escalation effect whereby more and more severe behaviours are exhibited due to increasing demands or frustration. SIB demonstrated some independence perhaps suggesting a different aetiology for SIB or a different mechanism of action. The relationships between other problem behaviours highlight that clinicians should enquire about presence of other types of behaviours when a person presents with one or more aggressive behaviours. Other, more subtle, behaviours may still present management difficulties but could be overshadowed by overt physical aggression, indeed, lethargy/social withdrawal was most strongly correlated with quality of life.

The age of onset for aggressive behaviour tends to be in childhood, indicating long-standing behaviours. The age of onset also suggests that early identification of those who exhibit aggressive behaviour may be particularly valuable to allow for early intervention, which may reduce the persistence or severity of aggressive behaviour into adulthood (Allen et al, 2013). Carers tended to seek medical help around three years after the behaviour first emerged; it may be useful to try and proactively identify those in whom aggressive behaviour is first emerging (Hastings & Brown, 2000). Evidence suggests that early intervention, particularly in SIB may be an effective strategy (Richman 2008; Reeve & Carr, 2000). Furthermore, it may be important to provide pedagogical support to carers, helping to explain the enduring nature of aggressive behaviour and the limitation this places on the success of interventions, to equip carers with the knowledge and support to manage these behaviours and to manage their expectations, as it is unlikely that aggressive behaviour will be eliminated in the long term. A study of a clinic for young children with developmental delay and aggressive behaviours, suggests that managing parents' expectations is an important target for intervention (Fox et al, 2007). Further research could investigate the reasons for the time lag between emergence and seeking medical help, with the aim of improving access to services.

The improvements in aggressive behaviour may have been as a result of clinical intervention, as all participants were in receipt of services. However, as most participants had been in contact with services for a long time and were not new referrals, it is likely that most interventions received were long-standing. As Emerson and Einfeld (2011) comment, studies of interventions suggest that reductions in aggressive behaviour may be achieved in the short-term but will rarely achieve complete elimination of the behaviour in the long-term. Further research could investigate the contribution of interventions by collecting longitudinal data on service utilisation. Of clinical note, the period of improvement and stability may allow for the withdrawal of some interventions, especially medication, with options of reintroducing these in the future. Improvements may also have been due to psychological changes in the carers, perhaps reflected in a reduction in carer's concerns.

CHAPTER 5: RISK FACTORS FOR AND ASSOCIATIONS WITH AGGRESSIVE BEHAVIOUR (SEVERITY AND TYPE OF AGGRESSIVE BEHAVIOUR)

Introduction

A risk factor is defined as ‘a characteristic, experience, or event that, if present, is associated with an increase in the probability (risk) of a particular outcome’ (Kraemer et al, 1997). Studies of risk factors for aggressive behaviour report varying results owing to differences in methodology, analyses, sampling, and definitions of behaviour (see Chapter 1, see also Darrow et al, 2011 for a review). Identification of risk factors remains an important goal for research in helping to help identify those most at risk of developing aggressive behaviour and to allow the implementation of early intervention (McClintock et al, 2003). Many studies of risk factors for aggressive behaviour investigate individual associations; this does not account for the overlap between factors found to be associated (Felce & Kerr, 2013). For example, Tyrer and colleagues (2006) found that all variables apart from ethnicity were individually associated with the presence of physical aggression; however, far fewer variables were associated when entered into multiple regression analyses to account for the overlap in variance between the variables (see Table 10). A meta-analysis by McClintock and colleagues (2003) highlighted these problems, resulting in the publication of seven papers that have addressed these issues by concentrating on topography of aggressive behaviour and accounting for overlap between risk factors using multiple regression analyses (see Table 10 for details of these studies). As previous reviews have summarised the literature on individual risk factors for aggression (see Cooper et al, 2009a; 2009b; McClintock et al, 2003), this chapter concentrates on reviewing the results of these ‘key’ studies along with systematic reviews and meta-analyses. Furthermore, the focus is on reviewing studies that included adults (or with separate data relating to adults) with ID who exhibit aggressive behaviour according to the definition employed in the present study (including individual types of behaviour).

Personal/Demographic Risk Factors

Intellectual Impairment

Increasing severity of ID has commonly been associated with aggressive behaviour (e.g. Crocker et al, 2006; Deb et al, 2001a: for SIB; Borthwick-Duffy, 1994). Tsiouris and colleagues (2011) report increased frequency of aggressive behaviour associated with increased severity of intellectual impairment for two of the five types of aggressive behaviour under investigation in their study, namely, physical aggression to others (Tyrer et al, 2006, also reported this relationship) and SIB whereas verbal aggression and property destruction demonstrated the opposite effect. Cooper and colleagues (2009a; 2009b) also found SIB and outwardly-directed aggression to be more common among those with more severe intellectual impairment. Lundqvist (2013) reported the same in relation to SIB only, whereas Drieschner and colleagues (2013) did not locate any associations with ID either for severity of total aggression or for individual types of aggression in their sample all with aggressive behaviour. Similarly, Aman and colleagues (1995) did not find any relationship with severity of overall aggression based on ABC-I scores.

Gender

Three of the key studies did not locate any gender associations with SIB, however, females were more likely to exhibit outwardly-directed aggression (including verbal aggression) (Lundqvist, 2013; Cooper et al, 2009a; Cooper et al, 2009b). Drieschner and colleagues (2013) report more severe total and individual types of aggression in females, complimenting the findings of some studies of individual associations (Tenneij & Koot, 2008: number of outwardly-directed incidents only, otherwise comparable; Aman et al, 1995). This is in contrast to other studies that have reported more severe/prevalent aggression in males, including a meta-analysis and two of the key studies examined here (Tsiouris et al, 2011; Crocker et al, 2006: property destruction; Tyrer et al, 2006:

physical aggression to others; McClintock et al, 2003: outwardly-directed aggression; Borthwick-Duffy, 1994; Harris, 1993: day centre setting only). It is a commonly held assertion that aggressive behaviour is associated with the male gender (Emerson, 2001), although some studies have reported SIB to be more common in females (Crocker et al, 2006; Deb et al, 2001a). However, Crocker and colleagues (2006) highlight from their study of individual associations that SIB was also more severe in those with more severe ID and more females had severe ID which could act as a confounder, accentuating the actual gender difference. This highlights the importance of controlling for other variables through multivariate analyses.

Age

Aggressive behaviour is commonly considered to increase with age until mid-adulthood (Davies & Oliver, 2013), however, studies have reported mixed results in terms of an overall relationship with age (Lowe et al, 2007a: association with physical aggression only; Hemmings et al, 2006, associations with SIB only; Deb et al, 2001a, no association; Nøttestad & Linaker, 2001, no association with SIB; Collacott et al, 1998b: association with SIB; Hillery & Mulcahy, 1997: no association with SIB; Leudar et al 1984: no association). Four of the aforementioned key studies did not find any associations with age, most consistently with SIB suggesting that such behaviour is persistent (Drieschner et al, 2013; Lundqvist, 2013; Cooper et al, 2009a; Cooper et al, 2009b; Danquah et al, 2009). The difference between studies may be explained by a shift in topography with age, for example, severity of verbal aggression to others increased in the study by Tsiouris and colleagues (2011) whereas all other types decreased. Tyrer and colleagues (2006) reported decreased prevalence of physical aggression to others with age. Lundqvist (2013) reported decreasing prevalence with age for outwardly-directed aggression with a second peak among those aged 70 or older. This may highlight a need to consider severity of individual types of aggressive behaviour, rather than overall aggression or prevalence of type (see Davies & Oliver, 2013 for a review of prevalence of aggression and age). Severity of SIB may be relatively stable whereas outwardly-directed aggression may decrease over time with a shift towards more verbal aggression, perhaps as these behaviours require less energy expenditure (Cohen et al, 2010). Longitudinal research is needed to examine, in detail, the topography of aggressive behaviour over time.

Verbal Communication

Lower levels of language skill have been associated with prevalence and severity of aggressive behaviours, especially SIB (Hemmings et al, 2013; Danquah et al, 2009; Crocker et al, 2006; Lowe et al, 2007a; Deb et al, 2001a; Nøttestad & Linaker, 2001; Moss et al, 2000; Bott et al, 1997; Chamberlain et al, 1993). A meta-analysis and systematic review also assert that SIB is associated with lower levels of expressive or receptive verbal communication (McClintock et al, 2003; Furniss & Biswas, 2012) with no association with aggression to others (McClintock et al, 2003). However, other studies have failed to locate individual associations when accounting for potentially confounding variables (Cooper et al, 2009a; 2009b).

Type of Residence

Higher levels of aggressive behaviour have been reported in institutional settings (Borthwick-Duffy, 1994), those not living with a family carer (including not living with any carer, living with a paid carer, in congregate community settings or institutions) (Cooper et al, 2009a; Cooper et al, 2009b, Freedman & Chassler, 2004; Harris, 1993) and living in group homes (Crocker et al, 2006; Tyrer et al, 2006). However, studies have also reported no association with type of residence (Wisely et al, 2002; Deb et al, 2001a; Nøttestad & Linaker, 2001; Hillery & Mulcahy, 1997; Harris, 1993).

Co-morbid Diagnoses/Physical Medical Conditions

Increased prevalence of aggressive behaviour has been linked to various physical conditions, although they remain rarely studied. An early study found that individuals with ID and poor physical health were more likely to be aggressive than those with better health, regardless of health issue (Davidson et al, 1994). A systematic review synthesised evidence published between 1990 and 2008 on the relationship between physical health problems and challenging behaviour in people with ID (de Winter et al, 2011). The authors used a broad definition of challenging behaviour that primarily included the behaviours under investigation in the current study. Eleven well-conducted studies are reviewed that report significant and independent associations between pain related to cerebral palsy, chronic sleep problems, urinary incontinence and visual impairment. Results were also suggestive of associations with gastrointestinal problems, menstrual cycle and sub-types of epilepsy. However, the authors comment that for some physical health conditions, no articles were identified. Furthermore, as the majority of studies were cross-sectional or retrospective, the authors specify a need for further longitudinal research that can delineate cause and effect.

Other authors have reported few associations with physical health conditions (Cooper et al, 2009a; Cooper et al, 2009b; Poppes et al, 2010; Deb et al, 2001a). For example, most authors report no relationship between epilepsy and aggression (Buono et al, 2012; de Winter et al, 2011; Poppes et al, 2010; Pawar & Akuffo, 2009; Matthews et al, 2008; Ring et al, 2007; Tyrer et al, 2006; Deb et al, 2001a; Espie et al, 2003; Collacott et al, 1998b; Aman et al, 1995; Deb & Hunter, 1991). However authors have reported associations with visual or hearing impairments (Cooper et al, 2009a; Nøttestad & Linaker, 2001; Collacott et al, 1998b) and urinary incontinence (Cooper et al, 2009b) and found mobility problems to be associated with presence of SIB (Poppes et al, 2010; Emerson et al, 2001a; Nøttestad & Linaker, 2001).

Psychiatric Disorders

As with prevalence of aggressive behaviour, prevalence of psychiatric disorder is considered common among adults with ID (Reid et al, 2013; Cooray & Bakala, 2005; Deb et al, 2001b; Moss et al, 2000; King et al, 1994). Numerous studies have reported an association between aggressive behaviour and psychiatric disorders, including anxiety disorders, psychotic disorders and mood disorders (Hurley, 2008; Myrbakk & von Tetzchner, 2008b; Hemmings et al, 2006; Rojahn et al, 2004; Holden & Gitlesen, 2003; Moss et al, 2000; Sovner et al, 1993; Lowry & Sovner, 1992), however, results across studies remain inconsistent, with some reporting little or no association (e.g. Allen et al, 2012; McCarthy et al, 2010; Rojahn et al, 2009; Lowe et al, 2007a) leading to the recommendation for further research with large samples sizes, prospective data collection and using standard rating instruments, as used in this study (Hemmings et al, 2013; Hemmings et al, 2006).

There are difficulties in diagnosing psychiatric disorders in people with ID, especially those with severe and profound ID, limited communication skills and co-morbid ASD (Hemmings et al, 2013; Ruedrich, 2010; Kannabiran & McCarthy, 2009; Matson & Shoemaker, 2009; Holden & Gitlesen, 2004; Deb et al, 2001b; Sturmey et al, 1991) which may lead to under-diagnosis and therefore under-reporting in studies where case file data is used. Authors have implicated 'diagnostic/behavioural overshadowing' whereby the presenting problems of aggressive behaviour could be indicative of an underlying psychiatric disorder, but serve to mask the condition with treating clinicians (especially non-specialists) giving excessive attention to the aggressive behaviour or the co-morbid ID, rather than investigating further (Hemmings et al, 2013; Deb et al, 2001a; Tsiouris, 2001; Lowry, 1997; Reiss & Szysanko, 1993). Conversely, over diagnosis may also occur, influenced by co-morbid physical health problems, lack of knowledge of carers, medication side effects (Hemmings et al, 2013; Deb et al, 2001b), health insurance systems or used as a justification for psychotropic medication prescription. This has led to wide ranging prevalence estimates (e.g. Bailey & Andrews, 2003) and difficulties in consistently identifying psychiatric risk factors.

Authors have hypothesised the reasons for the purported associations between psychiatric conditions and aggressive behaviour, identifying three potential mechanisms (e.g. Emerson, 2001). It has been suggested that the behaviours may represent atypical symptoms, especially in those with severe ID or limited communication skills (Bodfish et al, 1995), be behavioural equivalents of psychiatric disorder (Sturmey et al, 2010a; Clarke & Gomez, 1999; Marston et al, 1997) or may act as a personal setting event by lowering the capacity to cope with aversive environmental stimuli (Holden & Gitlesen, 2008; Hemmings et al, 2006; Rojahn et al, 2004; Tsiouris et al, 2003a; Carr et al, 1996; Lowry & Sovner, 1992). In this way, psychiatric disorders may have a direct causal or artefactual relationship (Felce et al, 2009).

Among the key studies, varied results relating to psychiatric conditions were reported. Cooper and colleagues (2009a; 2009b) did not locate any associations other than with ADHD. This is perhaps due to the use of the DC-LD as the diagnostic instrument, which excludes aggressive behaviours that are part of psychiatric conditions, physical illnesses, pervasive developmental disorders, and mental health problems. Similarly, Drieschner and colleagues (2013) only reported an association between ADHD/disruptive behaviour disorder and frequency of inpatient aggression whilst Lundqvist (2013) and Tyrer and colleagues (2006) reported no independent associations. Conversely, Tsiouris and colleagues (2011) specifically examined relationships between aggressive behaviour and psychiatric conditions and report independent associations for all psychiatric conditions under investigation (see Table 10). However, this study used clinical file reports of diagnoses by clinicians and the prevalence rates for psychiatric conditions are much higher than previously reported, suggesting potential over-reporting.

Autism Spectrum Disorder

ID and ASD commonly co-occur (Matson & Shoemaker, 2009; Deb & Prasad, 1994) with correlated severity (McCarthy et al, 2010; Vig & Jedrysek, 1999) and ASD has commonly been implicated as a risk factor for aggressive behaviour (Felce & Kerr, 2013; Hemmings et al, 2013; Tsiouris et al, 2011; McCarthy et al, 2010; Matson et al, 2009; Crocker et al, 2006; Crocker et al, 2007; McClintock et al, 2003). Tsiouris and colleagues (2011) report independent associations between diagnosis of autism, and physical aggression against others and property destruction. Conversely, others have reported no relationships with outwardly-directed aggression (Drieschner et al, 2013; Lundqvist, 2013; Cooper et al, 2009b; Tyrer et al, 2006). Two of the key studies report independent relationships between ASD and SIB (Lundqvist, 2013; Tsiouris et al, 2011).

Other Problem Behaviour

Few studies have investigated the associations between aggressive and other problem behaviour, especially over time and controlling for other potentially confounding variables. Existing studies have found individual associations between impulsivity, overactivity, presence of repetitive behaviours and aggressive behaviour (Oliver et al, 2009; Crocker et al, 2007; Bodfish et al, 1995). Furthermore, two of the key studies included other problem behaviour. Danquah and colleagues (2009) report an individual association between continued presence of SIB and presence of other challenging behaviour, however, few details are provided on how this was measured and this variable was no longer predictive in their multiple regression model. Drieschner and colleagues (2013) measured other problem behaviour using the Adult Behaviour Checklist and report that frequency of aggressive incidents after three months was associated with ‘externalizing’ behaviour, which includes ‘aggressive’, ‘rule breaking’, and ‘intrusive’ behaviour.

Severity of Aggressive Behaviour

As cross-sectional research is unable to consider previous aggressive behaviour as a predictor, it has rarely been researched. However, the limited existing longitudinal research suggests medium to strong individual correlations (above r=.59, Totsika et al, 2008). For example, an early study by Leudar and colleagues (1984) found that aggressive behaviour predicted 58% of the variance in behaviour two years later. Significant correlations have also been reported for longer time periods, up to 20 years (Taylor et al, 2011; Reid & Ballinger, 1995). Two of the 'key' studies were longitudinal, however, only one included previous aggressive behaviour in their analyses and report earlier aggressive behaviour to be the strongest predictor of behaviour three months later (Drieschner et al, 2013).

Existing studies report mixed results in relation to risk factors, however, certain variables have been emerged as potentially relevant. The majority of studies focus on identifying risk factors for presence of aggressive behaviours from an epidemiological perspective and using a cross-sectional design (Lundqvist, 2013; McClintock et al, 2003; Kraemer et al, 2000). To the author's knowledge, none have examined independent associations with severity of aggressive behaviour (including less severe behaviour) and sub-types of aggressive behaviour in a community-based, clinic sample of adults who all exhibit aggressive behaviour. The analyses presented here investigated factors identified in previous research that were independently associated with severity of aggressive behaviour, as well as presence of each of the four types of aggressive behaviour, using multiple (linear and logistic) regression analyses. Both cross-sectional and prospective risk factors were investigated. The results of such analyses may be useful to inform the development of methods to prevent or ameliorate aggressive behaviours (Felce & Kerr, 2013) and helps to develop aetiological hypotheses (Cooper et al, 2009a; 2009b). Allen and colleagues (2013) propose a three tier public health prevention model for behavioural and psychiatric disorders in which the identification of risk factors can assist with secondary prevention, described by the authors as ‘beating the odds’. Allen and colleagues (2013) suggest that accurate screening tools are required to identify those most at risk of developing aggressive behaviour. Therefore, research is required to reliably identify risk markers that could inform the development of screening instruments.

Table 10: Key studies of risk factors for aggressive behaviour using multiple regression analyses

Author Year	Topography of aggressive behaviour (Severity or prevalence)	N	Source of participants/ Setting/ Profile of participants	Categories of variables considered	Individual predictors (direction of association)
Drieschner et al 2013*	5 types measured by extended version of the MOAS: Verbal aggression Aggression towards objects Physical aggression Autoaggression (SIB) Sexual aggression (frequency, after 3 months)	218	Inpatient treatment facilities (n=2) The Netherlands Borderline-mild ID only (mean IQ=70) 86% male All with aggressive behaviour	Personal/demographic factors Dynamic Risk Outcome Scales (DROS) Adult Behaviour Checklist (ABCL) DSM IV diagnostic category IQ Global Assessment of Functioning (GAF) Previous aggression	Increasing frequency of incidents of any aggression: DROS Coping Skills (negative) ABCL scale Externalizing (positive) ADHD/DBD (present) MOAS+ incidents (months 1-3) (positive) Model R^2=.54
Lundqvist 2013	2 types measured by the BPI: Aggressive/ destructive (ADB) SIB (prevalence)	915	Community-based, receiving care from Local Health Authorities Sweden Administratively defined ID 55% male 62% with PB	Personal factors Disability/disorder Body functions Social activity/participation Services/treatment factors	SIB: ID level (more severe) Autism (present) Down syndrome (absent) Night time sleep disturbances (present) Tactile hypersensitivity (present) Communicating in pictures (present) Psychotropic medication (present) Model R^2=.24[a] ADB: Gender (female) Age (positive) Autism (present) Night sleep duration (negative)

					Auditory hypersensitivity (present) Communicating with signs (present) Group functioning (absent) Initiates social interaction (present) Psychiatry contact (present) Model R^2=.23[a]
Tsiouris et al 2011	5 types measured by modified version of the MOAS: Verbal aggression to others Verbal aggression to self Aggression towards objects Physical aggression to others SIB (frequency)	4,069	Community-based (small minority with family), receiving care services New York, USA Administratively defined ID 60% male 83% with aggression	Basic demographics Psychiatric conditions	Verbal aggression to others: ID (less severe) Age (positive) Depression (present) Bipolar disorder (present) Psychosis (present) Impulse disorder (present) Personality disorder (present) Verbal aggression to self: ID (less severe) Age (negative) Sex (females) Anxiety (present) Depression (present) Bipolar disorder (present) Psychosis (present) Impulse disorder (present) Personality disorder (present) Physical aggression to others: ID (more severe) Age (negative) Sex (males) Autism (present) Anxiety (present)

					Bipolar disorder (present) Psychosis (present) Impulse disorder (present) Personality disorder (present) Physical aggression to objects: ID (less severe) Age (negative) Sex (males) Autism (present) Anxiety (present) Bipolar disorder (present) OCD (present) Psychosis (present) Impulse disorder (present) Personality disorder (present) SIB: ID (more severe) Age (negative) Autism (present) Anxiety (present) Bipolar disorder (present) Psychosis (present) Impulse disorder (present) Personality disorder (present)
Danquah et al 2009*	1 type: SIB (prevalence, continued, after 2-4 years)	94	Community-based, receiving ID service, Manchester, England Administratively defined ID 49% male	Opiate-release/topography related Communication Medical/diagnoses Related behaviours Boredom/frustration Habitual	Self-biting (present) Verbal ability (lower levels)

Cooper et al 2009a 2009b	2 types: Outwardly-directed aggression SIB (prevalence)	1023	Community-based, receiving social care, specialist health services or known to GP Glasgow, Scotland Administratively defined ID 55% males 4.9% with SIB 9.8% with outwardly-directed aggression	Personal factors Lifestyle and supports Health and disabilities PAS-ADD Checklist Present Psychiatric State for Adults with Learning Disabilities	SIB: ID (more severe) Accommodation (not with family) ADHD (present) Down syndrome (absent) Visual impairment (present) Outwardly-directed aggression: Gender (male) ID (more severe) Accommodation (not with family) ADHD (present) Down syndrome (absent) Urinary incontinence (present)
Tyrer et al 2006	1 type: Physical aggression towards others (prevalence)	3062	Predominantly community-based, Leicestershire ID Register England Administratively defined ID 57% male 14% with physical aggression to others	Demographic factors Disability Assessment Schedule Co-morbid factors Psychological symptoms	Gender (male) Age (negative) Residence (NHS accommodation or residential home) ID (more severe) Down syndrome (absent)

*Longitudinal studies

[a] Nagelkerke R^2

ADHD: attention deficit hyperactivity disorder; DBD: destructive behaviour disorder; BPI: Behaviour Problems Inventory; PB: problem behaviour: ADB: aggressive destructive behaviour

Methods

Data on predictor/independent variables were collected during the first interview (T1, see detailed method in Chapter 2 and see Appendix 7). Selection of variables was informed by previous research which indicates that there may be a relationship with aggressive behaviour as outlined in the Introduction. As Field (2005) suggests, ideally, predictors in multiple regression should be selected based on previous (well-designed) research.

To allow adequate power to the analyses, some of the variables outlined in Chapter 3 were collapsed into binary categorical variables. These were pragmatic decisions based on clinical scenarios and were made in consultation with a statistician and a Specialist ID Consultant Psychiatrist. As only four participants were classed as having profound ID, the category was amalgamated with severe ID, and mild with moderate, to form two categories; mild-moderate and severe-profound. This is typical in the field whereby degree of impairment is often considered as comprising two groups (Emerson & Einfeld, 2011; BPS, 2000). Similarly, place of residence was dichotomised into family home (living with parents or siblings) or group community home (with 2+ residents) with daily support. Due to low representation, those who lived in their own home as sole occupant (N=3), with their own families (N=1), or at residential college (N=1) were excluded from any analyses investigating place of residence as a variable. All co-morbid diagnoses and health conditions were dichotomised into diagnosis/presence of condition or no diagnosis, to reflect clinical scenarios. Mini PAS-ADD thresholds were used to indicate presence or absence of specific psychiatric conditions.

By collapsing the categories in this way, a more balanced design was achieved, with more equal numbers of participants in each level of the independent variable, thus minimising problems of heterogeneity of variance between the groups in order to increase the power of the statistical analyses (Clark-Cater, 2001). Where a variable did not have adequate representation (n≤10) for each level, it was not included in analyses as it is possible that it would not have adequate power to detect any relationships and therefore would risk making a Type II error (Norušis, 2005). Furthermore, there would be a risk of incomplete information from predictors in logistic regression, whereby not all possible combinations of variables had representation. This arbitrary cut-off was decided upon in consultation with a statistician and Specialist ID Consultant Psychiatrist.

The independent/predictor variables were used to explore relationships with severity of aggressive behaviour and presence of the four different types of aggressive behaviour (verbal aggression, property destruction, SIB and physical aggression to others). ABC-I scores were used as the measure of severity of aggressive behaviour in the month preceding interview and MOAS subscale scores were used to indicate presence/absence of each type of behaviour. ABC-I was selected as the measure for severity of aggressive behaviour as opposed to the weighted MOAS scores, because it conforms to the assumptions of parametric statistical analyses, especially in relation to normality of distribution (Osborne & Waters, 2002). The independent/predictor variables comprise three groups, namely, participant characteristics (including standard demographic variables: place of residence, gender, degree of intellectual impairment, age of participant and expressive verbal communication), co-morbid diagnoses/medical conditions (epilepsy, physical disabilities, anxiety disorder, OCD, ASD, obesity/overweight, skin problems and gastrointestinal problems), and other problem behaviour (severity as measured by the ABC subscales). Initially, the relationships between the independent/predictor variables and aggressive behaviour at T1 were explored to investigate single time-point/cross-sectional associations, subsequent analyses sought to investigate prospective risk factors, using behavioural data collected at T2 and T3.

A staged process of analysis was performed, as recommended by Field (2005) and as used in previous longitudinal research (Drieschner et al, 2013; Hulbert-Williams et al, 2013; Lloyd & Hastings, 2008; Hastings et al, 2006; Lecavalier et al, 2006; Baker et al, 2003):

1) Initial analyses explored the univariate relationships between each independent/predictor variable at T1 and topography of aggressive behaviour at T1. Bivariate Pearson's, Spearman's (depending on the distribution of the data) and point-biserial correlations were performed to explore the relationships between data with at least one continuous variable and chi-square tests were used where both variables were binary (see Appendix 20 for the results of these analyses).
2) Where a predictor variable demonstrated a significant association with aggressive behaviour, a forced entry multiple linear or logistic regression analysis was performed using all the variables within the group to check whether the significant association was maintained when other variables were accounted for, this model-specific approach is similar to Cooper and colleagues (2009a; 2009b). For logistic regressions, odds ratios for the predictors are presented, which is the same as the exponential of the B coefficient (Szumilas, 2010).
3) Where significant independent predictors were maintained, they were entered into final forced entry regression analyses to model the behaviour at T1, including significant predictors from each of the three group-specific models (participant characteristics, co-morbid diagnoses/medical conditions, and other problem behaviour).
4) To examine the prospective predictive utility of the model, the variables in the final models at T1 were entered into forced entry regression analyses to model topography of aggressive behaviour at T2 and T3. Severity of aggressive behaviour at T1 was also included in these analyses as an independent/predictor variable.

Cross-sectional Associations with Participant Characteristics

There were no significant associations between any of the participant characteristics and severity of aggressive behaviour (see Table 1 in Appendix 20). However, prevalence of verbal aggression was significantly higher in females (n=43, 68.3% for males; n=33, 91.7% for females; $X^2(1)=7.04$, p=.008) and SIB was associated with more severe intellectual impairment (n=14, 25.9% for mild-moderate ID; n=28, 62.2% for severe-profound ID; $X^2(1)=13.24$, p<.001) and no language (n=18, 72.0% for no language; n=24, 32.4% for uses language; $X^2(1)=11.98$, p=.001) (see Table 2 in Appendix 20). There were no associations with property destruction or physical aggression towards others.

As there were no associations with severity of aggression, presence of property destruction or physical aggression towards others at T1, regression analyses were not performed for these outcomes. In the model for presence of verbal aggression at T1, gender significantly predicted presence of verbal aggression (see Table 11). In the model for presence of SIB at T1, only level of intellectual impairment significantly contributed to the model; expressive verbal communication ceased to be a significant predictor (see Table 12).

Table 11: Logistic regression analysis to model presence of verbal aggression at T1 from the participant characteristics at T1 (n=92)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	0.82 (0.86)			
Place of residence	-1.22 (0.73)	0.30	0.70	1.24
Gender	1.41* (0.70)	4.09	1.03	16.23
Level of ID	-1.21 (0.67)	0.30	0.80	1.11
Age	0.03 (0.03)	1.03	0.98	1.09
Expressive verbal communication	0.87 (0.72)	2.39	0.58	9.86

R^2= .11 (Cox & Snell), .17 (Nagelkerke). Model $X^2(5) = 10.95$, p=.52.
*p≤.05.

Table 12: Logistic regression analysis to model presence of SIB at T1 from the participant characteristics at T1 (n=92)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-1.05 (0.76)			
Place of residence	0.39 (0.58)	1.47	0.47	4.59
Gender	0.47 (0.51)	1.60	0.59	4.36
Level of ID	1.16* (0.56)	3.20	1.06	9.68
Age	-0.02 (0.02)	0.99	0.95	1.03
Expressive verbal communication	1.11 (0.62)	3.03	0.90	10.25

R^2= .17 (Cox & Snell), .23 (Nagelkerke). Model $X^2(5)$ = 17.46, p=.004.
*p≤.05.

Cross-sectional Associations with Co-morbid Diagnoses/Medical Conditions

Tables 3 and 4 in Appendix 20 present summary statistics for aggressive behaviour against each co-morbid diagnosis/medical condition under investigation. Aggression was more severe in those with a psychiatric condition (p=.007). When the types of psychiatric condition were investigated separately, both presence of anxiety disorder and presence of ASD were associated with more severe aggressive behaviour (p=.014 and p=.010 respectively). Occurrence of property destruction was more common in those without gastrointestinal and skin conditions (n=45, 62.5% without gastrointestinal problems; n=9, 33.3% with; $X^2(1)$=6.74, p=.009; n=47, 61.8% without skin problems; n=7, 30.4% with; $X^2(1)$=7.03, p=.008). SIB was associated with presence of ASD (n=26, 35.1% without ASD; n=15, 62.5% with; $X^2(1)$=5.58, p=.018). There were no associations with verbal or physical aggression towards others.

Multiple and logistic regression analyses modelled severity of aggression (see Table 13), presence of property destruction (see Table 14) and presence of SIB (see Table 15). Presence of psychiatric condition was not included in the severity of aggression model as it is an ‘umbrella’ variable comprising the other two variables entered into the analysis. Presence of anxiety disorder and presence of ASD both independently predicted severity of aggression (p=.031 and p=.026

respectively). Absence of gastrointestinal problems was independently associated with higher prevalence of property destruction (p=.027); absence of skin problems was not independently associated. ASD independently predicted presence of SIB (p=.042).

Table 13: Multiple linear regression analysis to model severity of aggression at T1 from co-morbid diagnoses and medical conditions at T1 (n=95)

			95% CI for B	
Predictor	**B (SE)**	**Standard. B**	**Lower**	**Upper**
Constant	13.22 (1.70)			
Diagnosis of epilepsy	-1.91 (2.03)	-0.10	-5.95	2.12
Presence of physical disabilities	2.55 (2.13)	0.13	-1.68	6.77
Presence of anxiety disorder	4.73* (2.16)	0.24	0.44	9.02
Presence of OCD	-2.74 (2.31)	-0.13	-7.34	1.85
Presence of ASD	5.33* (2.36)	0.25	0.64	10.02
Obesity/overweight	-0.28 (2.08)	-0.01	-4.41	3.86
Gastrointestinal problems	-1.93 (2.19)	-0.09	-6.28	2.42
Skin problems	0.11 (2.41)	0.01	-4.68	4.89

R^2=.15, Adjusted R^2=.07, p=.069.
*p≤.05.

Table 14: Logistic regression analysis to model presence of property destruction at T1 from co-morbid diagnoses and medical conditions at T1 (n=98)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	0.47 (0.41)			
Diagnosis of epilepsy	-0.43 (0.50)	0.65	0.25	1.72
Presence of physical disabilities	-0.23 (0.52)	0.80	0.29	2.20
Presence of anxiety disorder	0.84 (0.56)	2.32	0.78	6.89
Presence of OCD	-0.53 (0.57)	0.59	0.19	1.80
Presence of ASD	0.50 (0.59)	1.66	0.52	5.23
Obesity/overweight	0.83 (0.54)	2.29	0.80	6.54
Gastrointestinal problems	-1.20* (0.54)	0.30	0.11	0.87
Skin problems	-1.13 (0.58)	0.32	0.10	1.01

R^2= .18 (Cox & Snell), .24 (Nagelkerke). Model $X^2(8)$ =19.47, p=.013.
*p≤.05.

Table 15: Logistic regression analysis to model presence of SIB at T1 from co-morbid diagnoses and medical conditions at T1 (n=98)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-0.54 (0.40)			
Diagnosis of epilepsy	-0.71 (0.51)	0.49	0.18	1.33
Presence of physical disabilities	0.57 (0.51)	1.76	0.65	4.79
Presence of anxiety disorder	0.56 (0.51)	1.76	0.64	4.81
Presence of OCD	-0.22 (0.56)	0.81	0.27	2.43
Presence of ASD	1.15* (0.56)	3.14	1.04	9.50
Obesity/overweight	-0.57 (0.52)	0.57	0.20	1.57
Gastrointestinal problems	0.40 (0.51)	1.49	0.54	4.07
Skin problems	-0.45 (0.59)	0.64	0.20	2.02

R^2= .12 (Cox & Snell), .17 (Nagelkerke). Model $X^2(8) = 12.98$, p=.11.
*p≤.05.

Cross-sectional Associations with Other Problem Behaviours

As reported in Chapter 4, severity of all other problem behaviours, as measured by the ABC were positively correlated with severity of aggressive behaviour (ABC-I, p<0.05; see Appendix 19). A multiple linear regression analysis was conducted to determine their relative predictive utility (see Table 16). Stereotypic behaviour and hyperactivity/non-compliance were both significant predictors. Furthermore, presence of all four types of aggressive behaviour demonstrated some significant associations (p<0.05; see Table 5 in Appendix 20), logistic regression analyses were therefore performed for each (see Tables 17-20). None of the behavioural variables predicted presence of verbal aggression. Hyperactivity/non-compliance predicted presence of property destruction, stereotypic behaviour predicted SIB, and hyperactivity/non-compliance predicted physical aggression to others.

Table 16: Multiple linear regression analysis to model severity of aggression at T1 from severity of other problem behaviour at T1 (n=96)

			95% CI for B	
Predictor	**B (SE)**	**Standard. B**	**Lower**	**Upper**
Constant	7.27 (1.32)			
ABC-Lethargy, social withdrawal	.12 (.09)	.12	-.07	.30
ABC-Stereotypic behaviour	.49* (.22)	.23	.05	.92
ABC-Hyperactivity, non-compliance	.30** (.10)	.32	.10	.51
ABC-Inappropriate speech	.32 (.25)	.12	-.19	.82

R^2=.37, Adjusted R^2=.34, p<.001.
*p≤.05.
**p≤.01.

Table 17: Logistic regression analysis to model presence of verbal aggression at T1 from severity of other problem behaviour at T1 (n=96)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	.44 (.45)			
ABC-Lethargy, social withdrawal	-.04 (.04)	.96	.89	1.03
ABC-Stereotypic behaviour	.14 (.10)	1.15	.94	1.40
ABC-Hyperactivity, non-compliance	.04 (.04)	1.04	1.0	1.13
ABC-Inappropriate speech	.12 (.10)	1.12	.92	1.37

R^2= .09 (Cox & Snell), .14 (Nagelkerke). Model $X^2(4)$ =8.84, p=.07.
*p≤.05.

Table 18: Logistic regression analysis to model presence of property destruction at T1 from severity of other problem behaviour at T1 (n=96)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-1.06 (.42)			
ABC-Lethargy, social withdrawal	.02 (.03)	1.02	.96	1.08
ABC-Stereotypic behaviour	.03 (.07)	1.03	.90	1.18
ABC-Hyperactivity, non-compliance	.08* (.03)	1.08	1.02	1.15
ABC-Inappropriate speech	.02 (.08)	1.02	.88	1.19

R^2= .15 (Cox & Snell), .20 (Nagelkerke). Model $X^2(4)$ =15.32, p=.004.
*p≤.05.

Table 19: Logistic regression analysis to model presence of SIB at T1 from severity of other problem behaviour at T1 (n=96)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-.50 (.38)			
ABC-Lethargy, social withdrawal	-.01 (.03)	.99	.93	1.04
ABC-Stereotypic behaviour	.21** (.08)	1.24	1.07	1.43
ABC-Hyperactivity, non-compliance	-.01 (.03)	.99	.93	1.05
ABC-Inappropriate speech	-.08 (.08)	.92	.80	1.07

R^2= .17 (Cox & Snell), .16 (Nagelkerke). Model $X^2(4)$ =11.86, p=.018.
*p≤.05.
**p≤.01

Table 20: Logistic regression analysis to model presence of physical aggression to others at T1 from severity of other problem behaviour at T1 (n=96)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-1.74 (.45)			
ABC-Lethargy, social withdrawal	.03 (.03)	1.03	.98	1.10
ABC-Stereotypic behaviour	.03 (.07)	1.03	.90	1.17
ABC-Hyperactivity, non-compliance	.08** (.03)	1.09	1.02	1.16
ABC-Inappropriate speech	-.14 (.08)	.99	.85	1.14

R^2= .17 (Cox & Snell), .23 (Nagelkerke). Model $X^2(4)$ =17.76, p=.001.
*p≤.05.
**p≤.01

Final Models for Aggression at T1 and Prospective Prediction of Aggression at T2 and T3

Severity

The model comprising the four predictor variables for severity of aggression accounted for 38% of the variance in severity of aggression (p<.001) (see Table 21). Presence of anxiety disorder, ABC-stereotypic behaviour, and ABC-hyperactivity/non-compliance were significant independent predictors in this model. The same variables, as well as severity of aggression at T1 predicted 50% of the variance in severity of aggression T2 (see Table 22) and 54% variance at T3 (see Table 23). In both cases, severity of aggression at T1 was the only significant predictor.

Table 21: Final Multiple linear regression analysis to model severity of aggression at T1 (n=95)

			95% CI for B	
Predictor	**B (SE)**	**Standard. B**	**Lower**	**Upper**
Constant	6.84 (1.36)			
Presence of anxiety disorder	3.40* (1.71)	.17	.001	6.80
Presence of ASD	.38 (2.05)	.02	-3.70	4.45
ABC-Stereotypic behaviour	.52* (.22)	.25	.08	.97
ABC-Hyperactivity, non-compliance	.38*** (.09)	.40	.20	.56

R^2=.38, Adjusted R^2=.35, p<.001.

* p≤.05

***p≤.001.

Table 22: Final Multiple linear regression analysis to model severity of aggression at T2 (n=70)

			95% CI for B	
Predictor	**B (SE)**	**Standard. B**	**Lower**	**Upper**
Constant	2.16 (1.56)			
Severity of aggression at T1	.49*** (.10)	.53	.29	.69
Presence of anxiety disorder	3.02 (1.89)	.15	-.76	6.79
Presence of ASD	1.20 (2.15)	.06	-3.10	5.49
ABC-Stereotypic behaviour	-.01 (.23)	-.00	-.47	.46
ABC-Hyperactivity, non-compliance	.14 (.10)	.16	-.05	.33

R^2=.50, Adjusted R^2=.46, p<.001.

***p≤.001.

Table 23: Final Multiple linear regression analysis to model severity of aggression at T3 (n=56)

			95% CI for B	
Predictor	**B (SE)**	**Standard. B**	**Lower**	**Upper**
Constant	2.01 (1.68)			
Severity of aggression at T1	.44*** (.11)	.50	.23	.66
Presence of anxiety disorder	3.17 (2.02)	.16	-.89	7.22
Presence of ASD	-.24 (2.24)	-.01	-4.74	4.26
ABC-Stereotypic behaviour	.40 (.24)	.22	-.08	.87
ABC-Hyperactivity, non-compliance	.05 (.10)	.06	-.14	.25

R^2=.54, Adjusted R^2=.50, p<.0.001.

***p≤.001.

Verbal Aggression

Females were 5.12 times more likely to exhibit verbal aggression than males (CI 1.40-18.69) (see Table 24). However, gender did not predict presence of verbal aggression at T2 or T3 when severity of aggression at T1 was accounted for (see Tables 25 and 26) whilst severity of aggression at T1 was independently predictive. The model no longer significantly predicted presence of verbal aggression at T3 (p=.11).

Table 24: Final Logistic regression analysis to model presence of verbal aggression at T1 (n=99)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	.77 (.27)			
Gender	1.63* (.66)	5.12	1.40	18.69

R^2= .08 (Cox & Snell), .12 (Nagelkerke). Model $X^2(1)$ =7.94, p=.005.
*p≤.05.

Table 25: Final Logistic regression analysis to model presence of verbal aggression at T2 (n=75)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-.50 (.49)			
Severity of aggression at T1	.08* (.03)	1.08	1.02	1.15
Gender	-.49 (.52)	.62	.22	1.69

R^2= .10 (Cox & Snell), .13 (Nagelkerke). Model $X^2(2)$ =7.60, p=.022.
*p≤.05.

Table 26: Final Logistic regression analysis to model presence of verbal aggression at T3 (n=59)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-.33 (.54)			
Severity of aggression at T1	.06* (.03)	1.07	1.01	1.13
Gender	-.24 (.58)	.79	.25	2.45

R^2= .07 (Cox & Snell), .10 (Nagelkerke). Model $X^2(2)$ =4.41, p=.11.
*p≤.05.

Property Destruction

Gastrointestinal problems and hyperactivity/non-compliance predicted presence of property destruction (see Table 27). Those without gastrointestinal problems were 4.5 times more likely to exhibit property destruction. However, gastrointestinal problems were no longer predictive at T2 and T3 when severity of aggression at T1 was accounted for (see Tables 28 and 29). Hyperactivity/non-compliance remained predictive at T2.

Table 27: Final Logistic regression analysis to model presence of property destruction at T1 (n=96)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-2.09 (.62)			
Gastrointestinal problems	1.51** (.55)	4.51	1.55	13.15
ABC-Hyperactivity, non-compliance	.10*** (.03)	1.10	1.04	1.17

R^2= .21 (Cox & Snell), .28 (Nagelkerke). Model $X^2(2)$ =22.65, p<.001.
**p≤.01.
***p≤.001.

Table 28: Final Logistic regression analysis to model presence of property destruction at T2 (n=75)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-2.82 (.80)			
Severity of aggression at T1	.07* (.03)	1.07	1.00	1.14
Gastrointestinal problems	.91 (.61)	2.48	.75	8.25
ABC-Hyperactivity, non-compliance	.07* (.03)	1.08	1.01	1.14

R^2= .23 (Cox & Snell), .31 (Nagelkerke). Model $X^2(3)$ =19.80, p<.001.
*p≤.05.

Table 29: Final Logistic regression analysis to model presence of property destruction at T3 (n=59)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-1.54 (.75)			
Severity of aggression at T1	.01 (.03)	1.01	.95	1.08
Gastrointestinal problems	.34 (.66)	1.41	.40	5.05
ABC-Hyperactivity, non-compliance	.05 (.03)	1.05	.99	1.12

R^2= .08 (Cox & Snell), .11 (Nagelkerke). Model $X^2(3)$ =5.05, p=.17.

<u>SIB</u>

Level of ID remained a significant predictor of SIB at T1 (see Table 30) with participants having severe-profound ID being 3.31 times more likely to exhibit SIB when the other variables were accounted for. At T2 and T3, there were no independent predictors and the model ceased to predict presence of SIB at T3 (see Tables 31 and 32).

Table 30: Final logistic regression analysis to model presence of SIB at T1 (n=95)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-1.40 (.37)			
Level of ID	1.20* (.46)	3.31	1.34	8.20
Presence of ASD	.47 (.58)	1.60	.51	5.01
ABC-Stereotypic behaviour	.11 (.07)	1.12	.99	1.27

R^2= .17 (Cox & Snell), .22 (Nagelkerke). Model $X^2(3)$ =17.35, p=.001.
*p≤.05.

Table 31: Final logistic regression analysis to model presence of SIB at T2 (n=75)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-1.52 (.03)			
Severity of aggression at T1	.01 (.53)	1.01	.95	1.08
Level of ID	.94 (.53)	2.55	.90	7.24
Presence of ASD	1.06 (.68)	2.89	.77	10.83
ABC-Stereotypic behaviour	.06 (.08)	1.07	.92	1.24

R^2= .15 (Cox & Snell), .20 (Nagelkerke). Model $X^2(4)$ =12.32, p=.015.
**p≤.01.

Table 32: Final logistic regression analysis to model presence of SIB at T3 (n=59)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-1.50 (.65)			
Severity of aggression at T1	.03 (.04)	1.03	.96	1.10
Level of ID	1.13 (.61)	3.10	.94	10.23
Presence of ASD	1.14 (.73)	3.14	.75	13.17
ABC-Stereotypic behaviour	.00 (.08)	1.00	.85	1.18

R^2= .14 (Cox & Snell), .19 (Nagelkerke). Model $X^2(4)$ =8.90, p=.064.

Physical Aggression to Others

Hyperactivity/non-compliance was associated with presence of physical aggression to others at T1 (see Table 33). This variable was also predictive of presence of physical aggression to others at T2, even when accounting for severity of aggression at T1 (see Table 34), however, it was no longer predictive at T3 (see Table 35).

Table 33: Final logistic regression analysis to model presence of physical aggression to others at T1 (n=96)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-1.59 (.42)			
ABC-Hyperactivity, non-compliance	.09*** (.03)	1.10	1.04	1.16

R^2= .15 (Cox & Snell), .20 (Nagelkerke). Model $X^2(1)$ =15.69, p<.001.
***p≤.001

Table 34: Final logistic regression analysis to model presence of physical aggression to others at T2 (n=75)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-1.96 (.58)			
Severity of aggression at T1	.02 (.03)	1.02	.96	1.08
ABC-Hyperactivity, non-compliance	.06* (.03)	1.06	1.00	1.12

R^2= .09 (Cox & Snell), .13 (Nagelkerke). Model $X^2(2)$ =7.20, p=.027.
*p≤.05.

Table 35: Final logistic regression analysis to model presence of physical aggression to others at T3 (n=59)

			95% CI for Odds Ratio	
Predictor	**B (SE)**	**Odds Ratio**	**Lower**	**Upper**
Constant	-2.06 (.66)			
Severity of aggression at T1	.05 (.03)	1.06	.99	1.13
ABC-Hyperactivity, non-compliance	.02 (.03)	1.02	.96	1.09

R^2= .09 (Cox & Snell), .12 (Nagelkerke). Model $X^2(2)$ =5.31, p=.07.

Table 36: Summary of significant independent associations at each time point

Topography of behaviour	Time point	Predictor(s)	% variance explained
Severity	T1	Presence of anxiety disorder* Presence of ASD Stereotypic behaviour* Hyperactivity/non-compliance*	38*
	T2	Severity of aggression at T1* Presence of anxiety disorder Presence of ASD Stereotypic behaviour Hyperactivity/non-compliance	50*
	T3	Severity of aggression at T1* Presence of anxiety disorder Presence of ASD Stereotypic behaviour Hyperactivity/non-compliance	54*
Verbal aggression	T1	Gender*	12*[a]
	T2	Severity of aggression at T1* Gender	13*[a]
	T3	Severity of aggression at T1* Gender	10[a]
Property destruction	T1	Gastrointestinal problems* Hyperactivity/non-compliance*	28*[a]
	T2	Severity of aggression at T1* Gastrointestinal problems Hyperactivity/non-compliance*	31*[a]
	T3	Severity of aggression at T1 Gastrointestinal problems Hyperactivity/non-compliance	11[a]
SIB	T1	Level of ID* Presence of ASD Stereotypic behaviour	22*[a]
	T2	Severity of aggression at T1 Level of ID Presence of ASD Stereotypic behaviour	20*[a]
	T3	Severity of aggression at T1 Level of ID Presence of ASD Stereotypic behaviour	19[a]
Physical aggression towards others	T1	Hyperactivity/non-compliance*	20*[a]
	T2	Severity of aggression at T1 Hyperactivity/non-compliance*	13[a]
	T3	Severity of aggression at T1 Hyperactivity/non-compliance	12[a]

*Significant individual association/significant model; $p<0.05$.

[a] Care should be taken when interpreting these statistics as it is based on the Nagelkerke Pseudo R^2 estimation in logistic regression.

Discussion

This chapter investigated the relationships between topography of aggressive behaviour and various individual characteristics, including personal/demographic variables, co-morbid diagnoses/medical conditions, and severity of other problem behaviour, taking into account the potential overlap between these factors to identify independent cross-sectional and prognostic risk factors. Table 36 summarises the significant individual associations at each time point and the amount of variance explained by each model. The models for severity of aggressive behaviour accounted for a relatively large amount of variance (38-54%) with little difference between R^2 and adjusted R^2 indicating generalisability of the results. All models apart from presence of SIB and physical aggression to others were improved at T2, with the addition of severity of aggression at T1. However, the models tended to lose predictive power over time, from T2 to T3 (apart from severity of aggression) with the models for presence of the four types of aggressive behaviour ceasing to be significant predictors at T3. Several variables demonstrated relationships with severity of aggression, however, only presence of anxiety disorder and severity of hyperactivity/non-compliance demonstrated independent relationships at T1. No demographic variables were related to severity of aggression. The models for individual types of aggressive behaviour were less predictive and few demographic variables demonstrated any associations. At T1, females were more likely to exhibit verbal aggression; those with more severe ID were more likely to exhibit SIB; those without gastrointestinal problems or with more severe hyperactive/non-compliant behaviours were more likely to exhibit property destruction; and those with more severe hyperactivity/non-compliant behaviours were more likely to exhibit physical aggression to others.

To the author’s knowledge, there are no studies that have employed a longitudinal design involving a clinic sample of community-based adults with all types of aggressive behaviour with which to compare the present results. Two longitudinal studies exist that were either undertaken in inpatient settings or concentrated on prevalence of SIB alone (Drieschner et al, 2013; Danquah et al, 2009). Furthermore, as studies take into consideration different variables, use different statistical techniques to produce the models, sample different populations (e.g. population-based, those in contact with social care services/inpatient/clinic-based; profile of ID), and use different definitions of aggressive behaviour (e.g. frequency/prevalence/DC-LD), comparisons between studies remain difficult. Of particular note, is that none of the key studies outlined in Table 10 investigate severity of aggressive behaviour. In a study with children with ASD, Oliver and colleagues (2012) report different associations for severity and presence of behaviour and similar results were observed in this study.

Participant Characteristics – Demographic Profile

Intellectual Impairment

The most consistent finding across studies is the association between increasing severity of ID and SIB (Hemmings et al, 2013; Furniss & Biswas, 2012). The present study also found an association with SIB which persisted after accounting for a wide range of variables, with those with severe-profound ID being 3.31 times more likely to self-injure. Other studies have also reported this association (Lundqvist, 2013; Holden & Gitlesen, 2003; Deb et al, 2001a; Collacott, 1998b) including systematic reviews and meta-analyses (Furniss & Biswas, 2012), but reported no relationships with other types of aggressive behaviour (McClintock et al, 2003; Deb et al, 2001a). This may indicate that SIB has a biological aetiology shared with ID (Felce et al, 2009), complimenting existing research that has implicated biological systems (e.g. Sandman & Touchette, 2002; see discussion in Chapter 1). However, assessment of level of ID in the present study was based on a functional assessment, including consideration of daily living and social skills. Variation between studies may be partly accounted for by differences in measurement of ID, which was rarely formally assessed through IQ and functional tests.

Studies have consistently demonstrated relationships between SIB, daily living and social skills, however, the direction of influence is unclear as presence of SIB may impede the development of social skills (Furniss & Biswas, 2012; Kearney & Healy, 2011; Lowe et al, 2007a; Duncan et al, 1999). Furthermore, it has been suggested that ID is related to impairment in stress appraisal, which, along with difficulties appraising and processing information, limited behavioural repertoire, and a need for a structured and predictable environment, may increase the risk for psychological stress and produce SIB (Bramston & Fogarty, 2000; Bramston et al, 1999; Gardner & Sovner, 1994). Intervention may therefore seek to improve adaptive behaviour and social skills, however, most research has focussed on children, and therefore the effectiveness of such methods with adults is not yet known. Further research is needed to investigate the individual contributions and causality of functional and intellectual impairment which may further elucidate aetiology. For example, Matson and colleagues (2009) report negative social behaviours are related to aggression. Furthermore, the potential overlap between deficits in social skills, ASD and other psychopathology needs to be considered, especially with adults (Kearney & Healy, 2011), as discussed later.

Gender

Some studies have reported no gender effect (McClintock et al, 2003: SIB, meta-analysis including 7 studies; Lowe et al, 2007a; Crocker et al, 2006: overall severity, physical and verbal aggression to others; Deb et al, 2001a: physical aggression; Emerson, 2001; Nøttestad & Linaker, 2001: SIB; Collacott et al, 1998b: SIB; Linaker, 1994). The current study found that females were over five times more likely to exhibit verbal aggression. This may suggest that females are more likely to be referred for clinical input for this type of behaviour, which is perhaps more accepted by carers in males or that verbal aggression tends to be more severe in females thus requiring clinical input. Tsiouris and colleagues (2011) also report this association, however, only in relation to severity of verbal aggression directed towards the self. Currently, it remains difficult to locate a consistent gender association (Hemmings et al, 2013), however, emerging evidence may suggest that outwardly-directed aggression and, more specifically, verbal aggression may be more common or severe in females. The general aggression literature indicates few gender differences, however, males are more prone to physical aggression and females may utilise ‘less risky’ indirect methods of aggression (Archer & Coyne, 2005; Archer et al, 2004; Björkqvist et al, 1992). Further explorations should be guided by theoretical hypotheses rather than simply trying to locate a risk factor which may delineate any relationships, should they exist.

Verbal Communication

This study did not find any relationships with expressive verbal communication and, as with the study by Cooper and colleagues (2009a), located an individual association with SIB, but this relationship was not maintained when other factors were accounted for in the regression model. As discussed previously, this suggests that other factors, such as ID, are more important and thus highlights the importance of studying the relationships between factors themselves. Oliver and colleagues (2012) replicated this finding among children with severe ID and suggest that communication itself is related to ID, indeed, some authors have used level of communication as a proxy measure for level of ID (Moss et al, 2000). Furthermore, Furniss and Biswas (2012) caution against accepting the purported relationship as behavioural interventions, such as functional communication training, are not always successful and rarely eliminate SIB, perhaps suggesting a more complex aetiology that may relate to impairment in cognitive function or social skills.

Type of Residence

The present study found no evidence of an association with type of residence. It is impossible to draw conclusions about cause and effect from studies of the association with type of residence, as people may be in more secure or supportive settings due to their behaviours or the settings may contribute to their behaviour. Studies of deinstitutionalisation have reported mixed results on aggressive behaviour, with some suggesting improvements in behaviour after deinstitutionalisation and others reporting no effect (Bhaumik et al, 2009; Kim et al, 2001; Emerson & Hatton 1996; Young et al, 1998). Inconsistent findings across studies may indicate that specific residential features influence aggressive behaviour rather than broad residential category, therefore the investigation of contextual features of environments may provide insight (Darrow et al, 2011).

Co-morbid Diagnoses/Physical Medical Conditions

Increased prevalence of aggressive behaviour has been linked to various physical conditions (de Winter et al, 2011). Genetic conditions have also been implicated (see Chapter 1), however, they could not be investigated here due to low reported incidence in the sample (see Chapter 3). Conversely, presence of overall health conditions was not investigated due to a high proportion of the sample having some form of additional medical condition (See Chapter 3 and see O'Hara et al, 2010 for a comprehensive review of ID and ill health).

In accordance with previous studies, this study did not locate many relationships with physical health conditions (Cooper et al, 2009a; Cooper et al, 2009b; Poppes et al, 2010; Deb et al, 2001a). However, only a limited number of physical health conditions could be investigated so associations with some conditions may have been missed, such as hearing or visual impairments as only two participants were registered blind and six had a hearing impairment. As with previous studies, no associations with diagnosis of epilepsy were identified (Buono et al, 2012; de Winter et al, 2011; Poppes et al, 2010; Pawar & Akuffo, 2009; Matthews et al, 2008; Ring et al, 2007; Tyrer et al, 2006; Deb et al, 2001a; Espie et al, 2003; Collacott et al, 1998b; Aman et al, 1995; Deb & Hunter, 1991). Similarly, no relationship with obesity was reported (Sohler et al, 2009). Bhaumik and colleagues (2008b) investigated predictors of obesity in 1,119 adults on the Leicestershire ID register and did not find any independent association with behaviour problems when controlling for age, sex, ethnicity, smoking status and a wide range of other factors. Similarly, no relationships were found with physical disabilities, as has been reported in previous studies (Deb et al, 2001a). Other studies have found mobility problems to be associated with presence of SIB (Poppes et al, 2010; Emerson et al, 2001a; Nøttestad & Linaker, 2001), however, these tend to focus on more severe behaviours or more severe disabilities.

In contrast with de Winter and colleagues (2011), absence of gastrointestinal problems demonstrated a relationship with presence of property destruction at T1. The reasons for this are not clear and may suggest that property destruction may be related to an unmeasured variable that is also associated with absence of gastrointestinal problems. Similarly, absence of skin problems demonstrated an individual relationship, so these conditions may be considered protective factors. The aetiology of property destruction may be quite complex and may be more motivated by external factors rather than internal factors. However, the relationship may be spurious and it ceased to predict behaviour at T2 and T3, instead, severity of aggression at T1 was more predictive. Other authors have reported few, if any significant predictors of property destruction (Lowe et al, 2007a; Emerson et al, 2001a).

Psychiatric Disorders

Studies have reported difficulties in accurately diagnosing psychiatric disorders in people with ID (Hemmings et al, 2013; Kannabiran & McCarthy, 2009; Matson & Shoemaker, 2009; Holden & Gitlesen, 2004; Deb et al, 2001b; Sturmey et al, 1991). However, studies have demonstrated that diagnosis is possible but requires expertise and investment of resources that were outside the scope of this study (Cooper et al, 2007b; Tsiouris et al, 2003a; Tsiouris et al 2003b). Differences in existing studies may relate to the use of checklists, intended for screening for psychiatric disorders, as diagnostic tools which may be over inclusive (Tsiouris et al, 2011; Felce et al, 2009; Myrbakk & von Tetzchner, 2008b). Whilst the Mini PAS-ADD Interview, as used in the present study, has better predictive validity than the PAS-ADD checklist, this issue needs to be kept in mind when interpreting the results. Furthermore, despite the use of a well-established tool to assess psychiatric disorders, group membership was still informed by carer report. However, authors have commented on the potential bias in documented diagnoses made by clinicians, such as to justify the prescription of psychotropic medication, and suggest that rating scales serve to reduce this bias (Rojahn et al, 2004).

In the study by Tsiouris and colleagues (2011), bipolar disorder, psychosis, personality disorder and impulse control disorder were associated with all types of aggressive behaviour whilst others have reported no associations (Lundqvist, 2013; Tyrer et al, 2006). ADHD/impulse control disorders have been implicated by some (Drieschner et al, 2013; Cooper et al, 2009a; Cooper et al, 2009b). Such conditions were not evaluated here, precluding the potential to identify this association, as discussed in more detail later. Myrbakk and von Tetzchner (2008b) found that behaviour problems were associated with anxiety after controlling for level of ID, however, individual correlations with presence of types of aggressive behaviour were weak. Furthermore, Rojahn and colleagues (2004) report that more severe aggressive behaviour increased the risk of anxiety disorder among 180 adults with predominantly severe and profound ID. The present study found that anxiety disorder was independently related to severity of aggression at T1 after accounting for other variables. A review located only seven studies that investigated the relationship between anxiety and challenging behaviour, which all lend some support to an association, however, the authors conclude that the relationship has been little researched to date (Pruijssers et al, 2013). Studies that do not locate an association tend to be epidemiological studies that seek to identify associations with prevalence of aggressive behaviour. Anxiety disorder may mediate the response of an individual to external triggers, increasing the frequency or severity of already learned aggressive behaviour rather than uniquely causing the behaviour. In clinical practice, anxiety disorder may be neglected (Pruijssers et al, 2013), being overshadowed by aggressive behaviour and therefore the results highlight that it may be important to screen for anxiety disorder and provide appropriate treatment if it is indicated, however, this should be part of a multi-component treatment plan.

Some authors have implicated mood disorders in aggressive behaviour. For example, Tsiouris and colleagues (2011) report relationships between bipolar disorder and all the types of aggressive behaviour included in their study. Others have also reported relationships, especially with mania (Myrbakk & von Tetzchner, 2008b; Sovner & Hurley, 1983). Clinical diagnosis of bipolar disorder may be based on the episodic/cycling nature of aggressive behaviour, as described in the previous chapter. Therefore, differences between studies may reflect the use of a symptomatic screen as used in the present study compared with recording clinical diagnoses, as used in the study by Tsiouris and colleagues (2011). Conversely, no relationship with depression has been reported (Tsiouris et al, 2011: apart from verbal aggression; Sturmey et al, 2010b; Tsiouris et al, 2003a) whilst others have found a relationship with affective/depressive symptoms (Allen et al, 2012: physical aggression to others or property only; Hurley, 2008; Crocker et al, 2007; Hemmings et al, 2006). Such psychiatric conditions could not be investigated in this study due to low incidence in the sample, suggesting that these conditions may not be related to aggressive behaviour as all participants exhibited this behaviour.

Autism Spectrum Disorder

ASD is a commonly cited risk factor for aggressive behaviour (Felce & Kerr, 2013; Hemmings et al, 2013; Tsiouris et al, 2011; McCarthy et al, 2010; Matson et al, 2009; Crocker et al, 2007; Crocker et al, 2006; McClintock et al, 2003), however, results of individual studies have been mixed. Similar to the present study, no independent relationships with frequency of aggression among inpatients (Drieschner et al, 2013), prevalence of physical aggression to others (Tyrer et al, 2006) and aggressive-destructive behaviour (Lundqvist, 2013; Cooper et al, 2009b) have been reported. ASD was related to severity of aggression in the group-specific model but was no longer predictive when accounting for other variables. ASD is often associated with anxiety disorder (Matson & Shoemaker, 2009) which may explain why ASD was not an independent predictor when anxiety disorder was entered into the final model, as discussed in more detail below.

Two key studies report independent relationships between ASD and SIB (Lundqvist, 2013; Tsiouris et al, 2011), another reported an individual association that was not maintained when accounting for other variables (Cooper et al, 2009a). Other studies have also reported individual relationships between ASD and SIB (Furniss & Biswas, 2012; Lundqvist, 2013; McClintock et al, 2003; Collacott et al, 1998b). In the present study, both level of ID and ASD were related to presence of SIB, however, ASD ceased to be independently related when accounting for other variables, such as ID, anxiety disorder, and hyperactivity/non-compliance in the final model at T1. Other studies have reported the joint association between SIB, severity of ID and presence of ASD (Felce et al, 2009; Goldman et al, 2009). Severity of ASD has been linked to severity of ID (McCarthy et al, 2010; Vig & Jedrysek, 1999;

Deb & Prasad, 1994) and impulse disorder (Kozlowski et al, 2011), it is therefore not surprising there is a degree of overlap. These relationships may indicate an additive effect of symptoms relating to ASD, anxiety disorder and level of ID producing greater functional impairments (Matson et al, 2013), especially in relation to a restricted repertoire of behaviour, reasoning and adaptability which reduce an individual's ability to cope with stressful situations. Studies tend to report more associations with severity of SIB rather than presence (Furniss & Biswas, 2012; Bodfish et al, 2000; Cohen et al, 2010; Matson & Rivet, 2008a; 2008b), consequently, ASD may serve to increase the severity of behaviour.

McCarthy and colleagues (2010) studied challenging behaviour and psychopathology in adults with ID and ASD (n=124) compared with ID alone (n=562) and concluded that severity of ID and presence of ASD were the only individual predictors of severity of challenging behaviour when accounting for a range of other variables, including mental health problems. No independent relationships with ASD were identified which may relate to the focus on aggressive behaviour in this study instead of predicting presence of challenging behaviour and the definition of ASD used. The Mini PAS-ADD interview was used in this study whereas McCarthy and colleagues (2010) used clinical diagnosis using ICD-10 criteria. Clinical diagnosis of other psychiatric disorders was also used which, as the authors suggest, may have been prone to diagnostic overshadowing as described earlier. Therefore, anxiety disorder may be related to aggressive behaviours rather than broader, but more severe challenging behaviours (as measured by the Disability Assessment Schedule and therefore including a wider range of behaviours) that may be more related to ASD.

The present results do not support the notion of behavioural equivalence, whereby topography of aggressive behaviour is directly representative of an underlying psychiatric disorder as this varied widely among the sample. Other authors have found no support for the behavioural equivalence theory (McCarthy et al, 2010; Tsiouris et al, 2003a; Rojahn et al, 2004). Some have suggested that there may be behavioural equivalents for mania associated with bipolar disorders (Sturmey et al, 2010a), however, most of these behaviours are not aggressive in nature. In this way, behavioural equivalents of psychiatric illness may exist for some restricted conditions and behaviours, but it is unlikely that aggressive behaviour is purely the external manifestation of psychiatric psychopathology. Presence of a psychiatric disorder may predispose an individual to displaying aggressive behaviour, as symptoms in over half the sample were suggestive of a psychiatric disorder (see characteristics of the cohort in Chapter 3) and some significant relationships were identified. However, it is important to note that the screening instrument used may have been over inclusive. There is currently a paucity of good quality evidence of the effectiveness of psychotropic medications on aggressive behaviours (Deb et al, 2008; Tyrer et al, 2008; Deb et al, 2007; Deb & Unwin, 2007; Sohanpal et al, 2007). However, some studies have indicated that psychotropic medications are more effective when prescribed when features of an associated psychiatric illness are present (Hemmings et al, 2013) which suggests a partial correlation in some rather than equivalence. Hemmings and colleagues (2013) explain that common understanding suggests that ‘mental health and [aggressive behaviour] interplay in complex ways and that there are multiple reasons for [aggressive behaviour] with mental illness being only one of many possible causes or outcomes’ (p. 131).

Other Problem Behaviour

Drieschner and colleagues (2013) found an association between ‘aggressive’, ‘rule breaking’, and ‘intrusive’ behaviour and frequency of aggression. Features of these behaviours may be related to behaviours of hyperactivity/non-compliance that were found to be associated in the present study. Hyperactivity/non-compliance was independently predictive of severity of aggression at T1 and remained independently associated with both property destruction and physical aggression to others at T2 even after accounting for severity of aggression at T1. Lowe and colleagues (2007a) also reported an association between property destruction and hyperactivity/non-compliance. Therefore, such co-morbid behaviours may be a key target for intervention. As described in Chapter 4, quality of life, carer burden and concerns were all associated with other problem behaviour highlighting the potential impact of behaviours other than aggression on the person and those around them.

Behaviours relating to impulsivity, hyperactivity, non-compliance and repetition are associated with symptoms of impulse control disorder and ADHD (Tsiouris et al, 2011; Cooper et al, 2009a; 2009b). Studies, including some of the key studies, have reported associations between ADHD and impulse/conduct disorders and aggressive behaviour (Drieschner et al, 2013; Tsiouris et al, 2011; Cooper et al, 2009a; Cooper et al, 2009b; Rojahn et al, 2004), however these conditions were not studied here as they are not measured by the Mini PAS-ADD. The associations with hyperactivity/non-compliance may therefore indicate presence of these disorders among those who exhibit more severe aggressive behaviour, property destruction or physical aggression to others. However, carer report indicated that only four participants had received a clinical diagnosis of ADHD (see Chapter 3). This may reflect lack of carer knowledge of diagnosis or may relate to diagnostic overshadowing as described earlier. Such diagnostic overshadowing may be even more prevalent in child services, meaning few people with ID receive a diagnosis of ADHD in childhood. Diagnosis of ADHD in adulthood is complicated by the recall childhood symptoms, required for a diagnosis to be made. Therefore, a thorough screen for ADHD and impulse control disorder may be useful in clinical practice. Interventions for these conditions may be useful for aggressive behaviour, especially those that seek to increase functional skills such as impulse control.

Increased severity of stereotypic behaviour was associated with increased severity of aggression and presence of SIB (group-specific model only). Other authors have also reported these relationships among adults with ASD and children with severe ID (Richman et al, 2012; Oliver et al, 2012). However, stereotypic behaviour was not independently predictive when other variables were included in the regression model. This may due to the overlap between ASD and stereotypic behaviour, meaning neither accounted for unique variance. Kozlowski and colleagues (2011) report a correlation between symptoms of ASD and stereotypies and suggest a high degree of symptom overlap, although they conclude that symptom overlap does not account for the full relationship. Many authors have implicated disrupted executive function in behavioural problems associated with ASD (Roelofs et al, 2013). It has been suggested that rigid, repetitive and perseverative behaviours of people with ASD may be an indicator of executive-dysfunction, leading to impaired behavioural inhibition and problems regulating behaviour (Hill & Frith, 2003; Turner, 1999). However, a recent paper studying executive function in 50 adults with borderline to mild ID reported no differences between those with and without ASD (Roelofs et al, 2013). Therefore, both ASD and ID may result in impaired executive function potentially leading to aggressive behaviour. This could also provide support for the operant model of SIB that suggests it emerges from repetitive behaviours (Furniss & Biswas, 2012), however, causality cannot be inferred.

Severity of Aggressive Behaviour

As with the present study, Drieschner and colleagues (2013) reported an independent positive relationship between earlier aggressive behaviour and behaviour three months later, being the strongest predictor in their model. Severity of aggressive behaviour at T1 was by far the best predictor of subsequent aggressive behaviour six and 12 months later (standardised beta =.48 to .53) and was the only independent predictor suggesting a moderate degree of consistency over time. Similarly, severity of aggression at T1 was a significant independent predictor of subsequent presence of verbal aggression and property destruction. However, severity of aggression was not related to presence of SIB or physical aggression to others. This compliments the findings of Chapter 4 where it was reported that severity of SIB was independent of severity of other types of aggressive behaviour, whilst there was a large degree of overlap in prevalence. SIB might therefore have a certain level of independence and may not be associated with an escalation effect that could be present with verbal aggression or property destruction. The same may also be true for physical aggression to others. It is possible that some incidents of physical aggression can be severe but sporadic, with the person ‘hitting out’ without any preceding lower levels of behaviour.

Conclusions

This study represents a first attempt to longitudinally model aggressive behaviour among a community-based clinic sample of adults with ID. Totsika and colleagues (2008) comment that there are few studies available that have examined variables related to persistence of challenging behaviour and that no variables have emerged as systematically important. Overall, severity of earlier aggressive behaviour was most predictive of later severity of aggression, verbal aggression and property destruction. As severity of such behaviour demonstrates a degree of consistency over time, it may be important to record early levels of behaviour to identify those who exhibit more severe behaviour, and to ensure appropriate long-term support is offered to service users and carers.

Demographic variables are generally not good predictors of aggressive behaviour. This finding in effect compliments the widely varying existing research. It is also encouraging, given that these variables do not easily lend themselves to intervention. However, females were over five times more likely to exhibit verbal aggression. This relationship requires further study, as emerging evidence indicates that aggressive behaviour may be more prevalent in females, contradicting the commonly held assertion of an association with the male gender. The varying report of associations between gender and aggressive behaviour highlights a need for research that is guided by hypotheses of the underlying mechanisms between gender and behaviour.

Those with severe-profound ID were over three times more likely to exhibit SIB, being the only independent risk factor. As ID was assessed using a functional/adaptive behaviour assessment, this may highlight the importance of skills training to help alleviate the behaviour. Conversely, this may also indicate an organic basis for SIB, which is associated with ‘cognitive-behavioural sequelae (such as reduced attention span, poor impulse control, impaired memory etc.) [linked to] the neurological damage inherent in intellectual disability’ (Allen, 2000, p. 44). However, the aim of the present study was not to identify aetiology and therefore further research is needed to explore this. For example, Allen and colleagues (2013) comment that ‘at present, little is known about the process by which the risk markers... influence susceptibility to behavioural ....disorder’ (p.5).

A relatively robust model for severity of aggression was established accounting for a significant amount of variance in severity over time. However, around half of the variance remained unaccounted for. Predominantly, psychiatric and behavioural variables were included in the models which may be useful targets for intervention to reduce aggressive behaviour. For example, clinicians may want to assess for anxiety disorder or hyperactive/non-compliant symptoms suggestive of impulse control disorder and introduce interventions to manage these conditions. Identification of psychiatric conditions may lead to the implementation of appropriate and effective interventions such as therapy or medication, even where other factors may also be involved, in this way, multi-modal treatment is most likely to be effective (Felce et al, 2009; Hemmings et al, 2009). In the present study, only a limited range of psychiatric conditions were examined. Further longitudinal research should investigate the impact of psychiatric disorder in a more systematic way.

The results highlight the difficulties of locating long-term risk factors as most models ceased to significantly predict aggressive behaviour by the 12-month follow-up. This may be explained by the introduction of successful interventions, may suggest that risk factors change over time or may implicate other variables that were not under study in the present analysis. For example, transient environmental risk factors may play an important role. Hyperactivity/non-compliance was associated with severity, property destruction and physical aggression to others. The ‘non-compliant’ features such as ‘disturbs others’, ‘not cooperative’, and ‘ does not pay attention to instructions’ all relate to the social environment, thus highlighting the importance of interaction with the external environment. Matson and colleagues (2011) have suggested that internal factors may contribute in an indirect way, with environmental factors contributing more directly. It could also suggest that aggressive behaviour is episodic, fluctuating with changes in topography, but with a degree in consistency, as described in the previous chapter, and therefore it is impossible to identify permanent risk factors, instead, it is more appropriate to consider short-term risk factors.

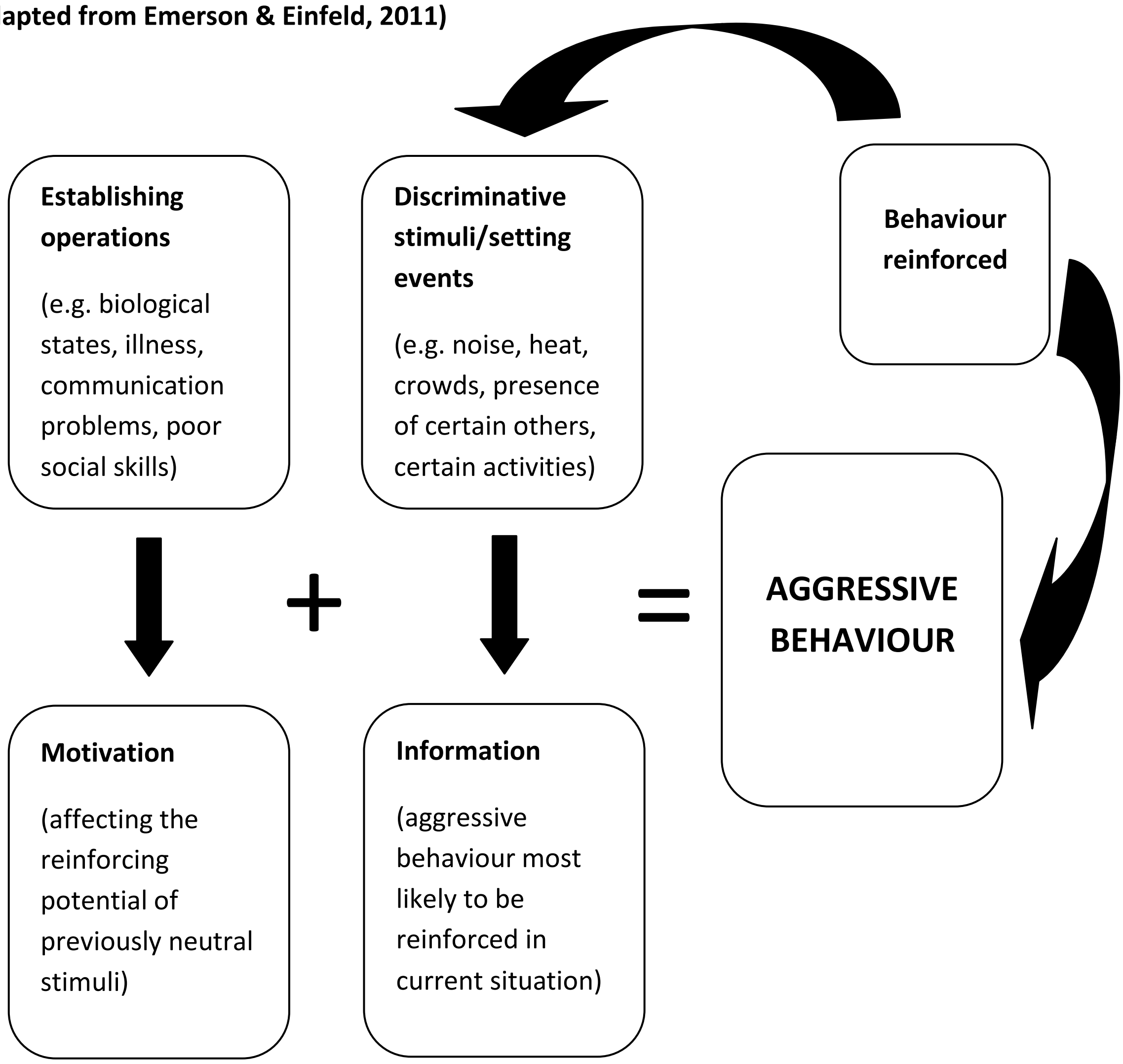
CHAPTER 6: CARERS' UNDERSTANDING OF CONTEXTUAL VARIABLES AND MOTIVATIONS FOR AGGRESSIVE BEHAVIOUR – A THEMATIC ANALYSIS

Introduction

Much existing research on risk factors for aggressive behaviour focuses on permanent or relatively stable personal characteristics such as gender, level of ID and comorbidities (McGill et al, 2005). Exploration of these variables is useful to inform clinical practice but is 'unlikely to have direct implications for intervention' (Hastings & Brown, 2000, p. 232). A leading approach to investigation, assessment and intervention for aggressive behaviour is functional assessment and analysis which some consider critical for the development of successful interventions (Emerson & Einfeld, 2011; Carr et al, 2008; Hanley et al, 2003; Hastings & Brown, 2000; Carr et al, 1999). Environmental factors for aggressive behaviour have most commonly been studied via functional assessment (Matson et al, 2011) which seeks to identify relationships between antecedents and reinforcing consequences (Didden, 2007) and to identify contextual variables and events that elicit aggressive behaviours (McGill, 1999) to determine *establishing operations* (now commonly termed *motivating operations*) that provide the motivational basis of behaviour in response to an otherwise neutral stimuli (Langthorne & McGill, 2009; Langthorne et al, 2007; Laraway et al, 2003; McGill, 1999; Smith & Iwata, 1997; Michael, 1993). Emerson and Einfeld (2011) included these features in their operant model for challenging behaviour (see Figure 8). A wealth of literature supports the notion of functional determinants for behaviour with specific functions relating to escape or receipt of attention, tangible items or demands often being cited (e.g. Matson & Vollmer, 1995; Carr & Durrand, 1985; Iwata et al, 1982), however, little empirical research has investigated contextual factors themselves in relation to their 'nature, mode and frequency of operation' (McGill et al, 2005).

Figure 8: Schematic Representation of the Operant Model of Aggressive Behaviour

(Adapted from Emerson & Einfeld, 2011)



Contextual variables comprise aspects of the individual and/or the environment and include *setting events* and *discriminative stimuli* (Carr & Smith, 1995). A discriminative stimulus is an event to which a response is consistently reinforced, often considered as the antecedent (Smith & Iwata, 1997; Skinner, 1938). Setting events are temporary features that mediate the relationship between the stimulus and response and may relate to the person themselves or characteristics of their environment (Allen, 2000; McGill et al, 2005; Kennedy & Itkonen, 1993; Bijou & Baer, 1978). For example, an adult with ID, living in a large, crowded, community home may exhibit verbal aggression in the form of shouting and swearing at meal times when there is a lot of noise. However, during quiet meal times, the same individual may not exhibit such behaviour. In this way, noise is the setting event which moderates the response to the stimulus of the presentation of food. Impairments in cognitive function leading to a reduced capacity to cope with demands could be construed as predisposing (personal contextual) factors with noise acting as a precipitating (environmental contextual) feature and the busy, often noisy environment of the home, especially during meal times acting as a perpetuating (historical environmental contextual) factor.

Contextual variables tend to include categories relating to biological (for example fatigue, illness or pain), environmental, including two categories relating to physical (for example, temperature or noise) and social (relating to other people), and instructional features, relating to tasks or activities (McAtee et al, 2004; Bijou & Baer, 1978). This compliments the dominant multi-determinant approach whereby aggressive behaviours result from a combination of biological, psychological, social and environmental factors (Emerson & Einfeld, 2011; Benson & Brooks, 2008; Deb et al, 2006; Gardner & Moffat, 1990). Various methods for functional and contextual assessments have been proposed with associated benefits and drawbacks (Carr et al, 2008). Experimental manipulation of variables (for example, experimental analogue assessments; Iwata et al, 1994a) allows for the inference of causality, however, this method is time-consuming, requires a high level of expertise and artificially producing aggressive behaviour using potentially aversive stimuli may be unethical (Carr et al, 2008; McAtee et al, 2004; Matson et al, 1999). Direct observation is also potentially resource intensive, especially if behaviours are not exhibited frequently (Carr et al 2008; McAtee et al, 2004). In response, the use of interviews and checklists with informants are the most preferred and widely used methods for functional assessment (Rojahn et al, 2012) to provide a simple, quick, accessible assessment, requiring less expertise on the part of the clinician (Carr et al 2008; McAtee et al, 2004; Desrochers et al, 1997). Clinician administered interview schedules for functional assessment have been developed, however, the reliability and validity of such instruments have not been evaluated (Matson & Minshawi, 2007).

A small number of checklists are available for the assessment of contextual variables. For example, Gardner and colleagues (1986) developed the Setting Event Checklist. McGill and colleagues (2005) further developed the checklist into an inventory of over 78 setting events for challenging behaviour in residential services. A wide range of setting events, derived from previous research and literature, were organised into nine categories to broadly cover all elements of the immediate environment, namely, physical setting, time of day, day of week, weather conditions, activities, presence of particular clients, presence of particular staff, social context, and personal context. In a study interviewing 66 care staff about 22 individuals with ID, the authors report that only 14 items were endorsed by at least 50% of carers as increasing or decreasing the likelihood of challenging behaviour suggesting that setting events varied widely (McGill et al, 2005).

The Contextual Assessment Inventory for Problem Behaviour (CAIPB) consists of 93 items, grouped into four categories, each with two or three subcategories, namely, social/cultural (including negative interactions and disappointments), tasks/activity (including factors related to tasks and daily routines), physical environment (including uncomfortable environment and changes in the environment) and biological (including medication and illness) (Carr et al, 2008; McAtee et al, 2004). The development of the checklist was informed by existing literature, checklists and expert opinion. The CAIPB has adequate convergent and predictive validity and test-retest reliability but questionable inter-rater reliability (Embregts et al, 2009a; Carr et al, 2008). Previously, Tustin and colleagues (1997) developed the Setting Event Inventory consisting of 155 items describing a wide range of possible antecedents. The checklist was developed using data from 92 adults with severe challenging behaviour to conduct a factor analysis that produced 19 scales, six of which measure preceding behaviours of individuals and 13 relate to the environment (including carer attention, instruction, and touch; criticism or correcting; peer agitation or encroachment; possessions; task difficulty, organised activity; noise; change and disappointment). The authors report good inter-rater reliability and internal consistency. However, the checklist does not consider personal contextual variables such as biological setting events.

McGill and colleagues (1999) suggest that sometimes it may be difficult to locate a function and suggest that the systematic assessment of contextual issues may be useful in practice. Martin and colleagues (1999) also highlight limitations in functional analysis methods in consistently finding a function. Research has demonstrated that even where functions can be identified, behaviours are still influenced by context (McGill et al, 2005; McGill, 1999). The complexities of functional analysis lie in the idiosyncrasies of behaviour as ‘there is no clear link between topography and function,... maintaining factors... may vary over time and across contexts... [and] behaviours may be multiply controlled by different contingencies of reinforcement and may reflect a combination of biological and behavioural processes’ (Emerson & Einfeld, 2011, p. 70). In developing the Questions about Behavioural Function (QABF), a tool to aid functional analysis, Matson and colleagues (1999) reported that it clearly identified functions for aggressive behaviour for 74-83% of their sample indicating that for 17-26%, clear functions could not be located. Furthermore, in a ground-breaking study by Iwata and colleagues (1994b), even after extensive experimental functional analysis, functions could not be determined for 4.6% of individuals with ID and SIB.

Functional analysis is a sophisticated, demanding, resource intensive process and is therefore difficult to implement by untrained clinicians and carers (Emerson & Einfeld, 2011; Matson et al, 2012a; McAtee et al, 2004; Paclawskyj et al, 2000; Applegate, 1999; Sturmey, 1995) and is subsequently rarely available (Robertson et al, 2005). Such analysis leads to the development of behaviour support plans whereby recommendations are made to address ‘context, skills repertoires, differential reinforcement, and engagement in quality-of-life activities or practices’ (McClean & Grey, 2012, p. 221; May, 2011; McClean et al, 2007; Carr et al, 2002; Hastings & Brown, 2000; Carr et al, 1999, see Dunlap & Carr, 2007 for a review). Such assessments and formulations in both clinical and research settings are usually developed by trained specialist psychologists or nurses and require time, resources and expertise and despite having proven efficacy in a range of settings, a major difficulty remains in the widespread implementation in natural service settings (McVilly et al, 2013; McClean & Grey, 2012; Carr et al, 2008; McClean et al, 2007; Johnston et al, 2006; Allen et al, 2005; McAtee et al, 2004; Emerson, 2001; Carr et al, 1999). Despite this, positive behavioural support is now a preferred method for intervention in challenging behaviour (Allen et al, 2005; Hieneman & Dunlap, 2000; Pelios et al, 1999), not least since the recent Winterbourne View abuse scandal as it represents a constructional, person-centred approach that, rather than considering behaviour as pathological, focuses on improving quality of life (Koegel et al, 1996; Goldiamond, 1974).

Commonly, carers acting as mediators are responsible for implementing behavioural plans on a day-to-day basis, often requiring behaviour change on their part (Hastings & Brown, 2000; Allen, 1999; Desrochers et al, 1997; Carr & Durrand, 1895). Lack of behavioural knowledge and understanding may present barriers to the successful implementation of the plans and may adversely affect interactions between carers and people with ID, causing the carer to attempt to avoid the behaviour (Hutchinson et al, 2012; Willems et al, 2013; Emerson et al, 2000; Hieneman & Dunlap, 2000; McKenzie et al, 1999; Oliver, 1995; Hastings & Remington, 1994; Hall & Oliver, 1992). Recently, McClean and Grey (2012) reported that the only factor associated with the effectiveness of positive behaviour support plans was treatment acceptability, rated by paid carers who were responsible for implementing the plan. Furthermore, ‘buy in’ with the intervention and ‘capacity of carers, including knowledge of behavioural support principles and practices’ were commonly highlighted by family members, direct care workers and clinicians when interviewed about factors affecting the outcomes of community-based behaviour support plans (Hieneman & Dunlap, 2000, p. 166).

Training in behavioural techniques has been shown to improve the skills of paid carers and the behaviour of the person and carer psychological factors have been shown to mediate carer stress, burnout and placement breakdown (Rose, 2011; Phillips & Rose, 2010; Grey & McClean, 2007; Lowe et al, 2007b; McClean et al, 2007; McClean et al, 2005; Hatton et al, 2004; Hastings & Brown, 2000). It may therefore be useful to explore the knowledge, experience and understanding of functions and contextual variables of carers who provide care to a person with ID who exhibits aggressive behaviour to identify potential knowledge gaps that could be targets for intervention with carers. Little is known about carer’s (especially family carers’) understanding of contextual factors and functions for aggressive behaviour. Currently, carers may not be directly involved in developing behaviour support plans and may therefore lack the investment and incentive to implement them. Furthermore, carers may even feel blamed by the support plans whereby their interactions with the person are implicated in precipitating aggressive behaviour. Involving carers in the development of plans may improve understanding and investment and thus improve intervention fidelity. The results of the present analysis may act as a guide as to how carers might be involved in developing interventions by elucidating their current understanding.

The limited research into contextual factors is often based on small samples of individuals in residential facilities which may not be representative of the wider ID population (Embregts et al, 2009a; Carr et al, 2008). This may be especially problematic as aggressive behaviours are known to be idiosyncratic and therefore contextual factors may vary widely across individuals and settings. Therefore, an aim of the current chapter was to identify a range of commonly occurring contextual variables, known to carers of a large sample of adults who exhibit aggressive behaviour and then organise them using formal qualitative methods to identify categories of contextual variables. The author is not aware of any existing studies that have taken this approach, especially including those who live in family homes. Knowledge of how carers perceive these variables and how this understanding relates to existing models from functional analysis and contextual factors may inform future service provision. The present chapter does not attempt to develop a model of aggressive behaviour but rather represent the understanding and experience of carers.

Methods

During the first interview, each carer was asked to generate a list of known contextual factors or motivations for aggressive behaviour displayed by the person they care for (the participant). Each carer was asked, “Do you know of any triggers for the aggression or what motivates the aggression?” (see Appendix 7 and Chapter 2 for a full description of the interview process). The term ‘triggers’ was used as it was felt to be more understandable, less technical and broader than other terms used in the literature such as ‘contextual variable’ or ‘setting event’. Similarly, the term ‘motivates’ was used instead of ‘functions’ for the same reason. Triggers in this context refer to predisposing events as well as situations or circumstances which commonly precipitate and sometimes maintain aggressive behaviour of the individual.

Carers’ responses were written down as close to verbatim as possible by the researcher then typed up into a Microsoft Word (2007) file to allow for analysis. The names of the participants were removed to maintain anonymity (P is used instead of names of individuals with ID) and sometimes notes were used to record the trigger or motivation described rather than a full verbatim account. However, this was discussed with and agreed upon by the carer. Additional triggers/motivations were noted as they were identified through further discussions in the interview in an attempt to capture all known triggers/motivations.

Thematic analysis was used to summarise the data. Braun and Clark (2006) suggest that ‘thematic analysis is a useful and flexible method for qualitative research’ (p. 77). Their paper provides an outline and guide to conducting a thematic analysis. Thematic analysis is not driven by epistemological positions or theoretical frameworks and its flexibility and accessibility makes it an appropriate analysis method for analysing the present data. As Braun and Clark (2006) suggest, thematic analysis allows for the generation of codes and themes from data, as with grounded theory, without the need to produce a full theoretical model. They remark that ‘thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data’ (p. 79) and can summarise key features in a large data set. In the present context, thematic analysis is used within a realist approach and so carer’s experiences are articulated by their language in a straightforward way.

The thematic analysis followed the methods outlined by Braun and Clarke (2006). It sought to provide a rich and accurate description of the entire data set by identifying repeated patterns. Themes were identified in an inductive (‘bottom-up’) approach to ensure that the themes identified were data driven, rather than driven by pre-existing theoretical models. As with the philosophy of a ‘bottom up’, ‘data driven’ approach, the analysis was performed without reference to existing research literature, representing an ‘atheoretical’ approach. The researcher utilised ‘bracketing’ to consciously distance themselves from the literature and allow the themes to emerge from the data. The aim was to accurately represent carer’s understanding of triggers and motivations for aggressive behaviour: what they identify as a precursor, rather than establishing the ‘fit’ of carer’s experiences with existing models. A secondary narrative analysis outlined in the discussion, therefore contrasts the carer’s descriptions with existing models of functions and contextual variables.

The themes aimed to provide a description of semantic patterns in the data (Braun & Clark, 2006). Familiarity with the data set was established by typing up the responses from the relevant questions during the interview. Furthermore, as a single researcher (GU) collected and analysed all the data, some initial analytic thoughts emerged during data collection. The entire data set was read and re-read and initial note taking sought to highlight patterns and meanings of interest and generate a list of ideas. Further reading of the text sought to identify initial codes. All the data were then coded by highlighting relevant text within each data item. Each code was collated by copying the relevant highlighted text into a separate electronic file, under the relevant code headings. Analysis of the collated codes developed the codes into potential broader themes. Visual representations of codes and themes were used to facilitate this process (e.g. thematic maps) and to start identifying candidate themes and subthemes with relevant extracts of data. These candidate themes were then reviewed and refined to devise the final themes with subthemes, each containing coherent data from the transcript, being distinct from each other, and providing an accurate representation of the data. The reviewing process took two stages: examining the themes at the level of each individual theme and the accompanying coding and at the level of the entire data set and full thematic map of the data. The entire data set was therefore re-read and re-coded using the refined themes. Each theme was defined using direct quotes and analytic narrative, then interpreted and finally, contrasted with existing literature.

To provide a validity-check of the analytical process and results, a trainee psychiatrist specialising in ID (ST) but largely naive to much behavioural literature independently completed a thematic analysis. The author and ST discussed their themes and coding and had both generated similar results.

It is acknowledged that a detailed qualitative analysis of the data was not possible as interviews were not tape recorded. However, as the aim was to answer a specific question, the transcript provided adequate information from the verbal account to conduct the present analysis and the transcript was an accurate reflection of the response given by the carer. Braun and Clarke (2006) suggest that these are the most important elements of a reliable transcript therefore the method of data recording is considered appropriate.

Results

Six themes were identified in the carer's accounts, namely internal (within the person) environment, external (outside of the person) environment, expression of volition, specific activities and events, characteristics of ID and predictability of behaviour. The coding of themes accounted for almost all the text. An analysis of the text leftover was conducted in case any further themes could be identified or whether emerging themes should be altered to accommodate the omitted material. For example, in the early stages of analysis, a theme called 'miscellaneous' was coded. Analysis of this theme generated an additional theme being identified, namely 'specific activities and events.'

The following presents a narrative description of each theme and subtheme and an analysis of how the themes relate to each other. Table 37 indicates how many carers endorsed each theme and subtheme. Carers tended to identify multiple contextual variables and motivations so there is some overlap. Table 38 provides illustrative quotes to support the narrative analysis.

Table 37: Prevalence of themes and subthemes

Theme/ Subtheme	**Number of carers mentioning theme** (N=100)
External Environment	**92**
Physical environment	54
Social environment	75
Internal Environment	**76**
Aversive physical states	22
Medical conditions	28
Mental health problems	15
Emotional states	58
Expression of Volition	**65**
Goal-directed behaviour	8
Limits to volition	63
Characteristics of ID	**57**
Problems with adaptability/uncertainly	54
Communication difficulties	16
Predictability of Behaviour	**45**
Behaviour is unpredictable	41
Behaviour is predictable	5
Specific Activities/Events	**26**
Specific activities	16
Specific events	13

External Environment

A theme relating to the person’s external environment was identified comprising two subthemes relating to the person’s physical or social environment.

Physical Environment

The physical environment refers to the person’s immediate physical surroundings. Triggers within this subtheme can be further categorised in terms of whether they relate to the auditory, visual or spatial environment, however, some relate to all or a combination. Carers identified both general/broad and specific auditory triggers. The latter included ‘the noise of lorries’, ‘road sweeps’, ‘busy pubs – this is more an issue of noise rather than crowds’, ‘fireworks and unpredictable noises.’ Commonly, triggering noises related to people or to a more general noisy environment and unexpected noises were particularly singled out.

Specific visual triggers were also reported with some relating to auditory triggers, for example, the sight of fireworks with the ‘flashing of lights’ was implicated as both a visual and an auditory trigger. Similarly, ambulances and fire engines were implicated for both their sight and the sound of their sirens. Watching certain programmes on television was also mentioned, particularly those with aggressive or gory content.

Often, spatial aspects of the physical environment were mentioned, mainly concerning busy or crowded places. This also links with visual and auditory stimuli contributing to the feeling of a busy/crowded atmosphere, and many of the spatial triggers for aggression concerned people and crowds. Some carers also alluded to the atmosphere of certain specific environments, such as day centres or the residential care home, again focussing on their busy nature. The carers also discussed the process whereby the external physical environments can impact on internal environments, which can then lead to aggression. Proximity of others was also often mentioned, including a sense of invasion of personal space.

All the aforementioned external stimuli are closely related as most co-exist to create a holistic external physical environment. Most commonly, issues around a noisy, busy, crowded environment were implicated with visual, auditory and spatial stimuli contributing to an atmosphere that is perceived as unpleasant. People were usually implicated as creating/being responsible for features of the physical environment, in this way, the physical and social environment are linked as an aspect of the environment which is external to the person.

Social Environment

The social environment was the single most reported subtheme and refers to interactions with others including other's interactions with the participant, the participant's interactions with others, or interactions observed by the participant between others. Aggressive behaviour was often motivated by attention, as one carer stated, 'a lot seems to be to do with attention.' Whilst now commonly regarded as an old fashioned concept, many carers felt that the aggressive behaviour was 'attention seeking'. Some carers suggested the behaviour was to initiate 'interaction' and that the participant did not mind whether this interaction was negative or positive with the main goal to 'get a reaction' from someone. Not all behaviour was to deliberately seek interaction/attention, some carers suggested that it was perhaps a jealous response to others getting attention. Other carers suggested that behaviour was because the person felt ignored.

Another feature of the social environment was the potentially precipitating effect of family. For some, it was the lack of family contact, whilst for others, it was seeing their family. This is clearly linked to internal emotional states as the carers identify excitement or anxiety relating to the visit as a contributing factor to aggressive behaviour. Other family contact was identified as aversive, in that it was conflict with family members which triggered aggression. Other carers indicated that it was due to a feeling of rejection from seeing family, perhaps because the participant no longer lived with them or because they rarely saw their family.

The issue of social conflict was also commonly mentioned. For some, it was in relation to the participant themselves conflicting with others. Elsewhere, it was the participant witnessing conflict or it was more an issue around confrontation. A particular trigger for those living in community homes was conflict with other residents in the home, and in some cases also with particular staff members. These ‘clashes’ were often described as being triggers for aggressive behaviour. Carers also indicated that some aggressive behaviour was retaliatory in response to other people being confrontational towards the participant. For others, the issue of confrontation was more subtle, with aggressive behaviour arising in response to people disagreeing with the person, ‘criticising them’, ‘correcting them’, or ‘telling them off’. Other confrontational/conflict situations could also trigger aggression, even when the participant was not involved and was simply observing the conflict.

Internal Environment

Carers spoke of triggers that were internal to the person, describing an element of their internal environment, including specific medical, psychological conditions and broader physical and emotional states.

Aversive Physical States

Carers identified various aversive physical states that could lead the person to displaying aggressive behaviour. These are distinct from the second subtheme as they are more general physiological states, as opposed to a specific medical condition. Identified states included hunger, thirst, feeling too hot, feeling tired or feeling poorly. Pain was implicated as a key trigger in some cases. One carer suggested that a pain killer was often effective as an intervention for aggressive behaviour, thus providing evidence that underlying pain may be the cause for the behaviour.

Medical Conditions

Specific medical conditions were identified and implicated by carers, these included the menopause, pre-menstrual tension, urinary tract infections, diabetes, epilepsy and gastrointestinal problems. Whilst such medical conditions are often associated with aversive physical states, such as pain, this subtheme is distinct from the previous subtheme, as it details very specific medical conditions that could be considered as medical risk factors. Conversely, the previously highlighted aversive physical states may exist without a specific medical condition being present.

Mental Health Problems

Carers talked about specific mental health problems, including allusions to deterioration in mental health, as precipitating aggressive behaviour. Specifically, the following mental health problems were mentioned: ‘depression’, ‘psychotic episodes’, ‘elevated mood’ ‘linked to manic episodes’ and ‘paranoia related to psychotic illness.’ Two carers explicitly linked depressive episodes to SIB, although symptoms of bipolar disorder and psychosis were linked to more outwardly-directed aggression.

Emotional States

As with internal physical states, carers identified various broad internal emotional states that could trigger aggressive behaviour. This subtheme is linked to, but distinct from, mental health problems. Whilst many mental health problems are associated with unpleasant emotional states, such as anxiety, they are considered separate categories that can exist independently. For example, a person can experience anxiety as an adaptive response to stimuli and, therefore, it would not constitute a mental health problem. Similarly, someone can experience unhappiness without being depressed.

Many carers described unpleasant emotional states. However, carers also commented on the more positive emotional state of excitement: ‘when P is too excited’ and offered descriptions of how excitement could turn into a more negative emotional state. The notion of excitement is linked to the idea of over-arousal, mentioned explicitly by some carers. Anxiety was also commonly implicated, with some carers indicating that it underpinned much of the person’s aggressive behaviour. Other aversive emotional states included ‘agitation’, ‘feeling out of control’, ‘being unhappy’, ‘feeling frightened or not feeling secure’, or feeling ‘under pressure or when she is stressed’ and also often ‘boredom’.

Some carers also mentioned issues around sensitivity, particularly concerns over the thoughts of others. It is likely that some of these internal emotional states are provoked by circumstances within the external environment, such as the aforementioned boredom, possibly due to lack of stimulation (either in the physical or social environment). However, some of these emotional states may be more enduring features of the person’s internal environment; for example, the person may be prone to anxiety. The internal and external environments are likely to be related as one has the potential to affect the person’s relationship with the other.

Expression of Volition

This theme refers to issues around the person expressing free will. Some behaviour was described as explicitly goal-directed, however, often carers’ accounts did not implicate goal-directed behaviour and instead aggressive behaviour was in response to the person not having their wants or needs met. Similarly, some carers suggested that the behaviour was in response to demands being made of the person (for example completion of a daily life activity) although the carer did not state that it was intentionally motivated to avoid doing this task. Therefore, two subthemes emerged, one of overt goal-directed behaviour and the other a more general response to limits to volition.

Goal Directed Behaviour

In some cases, the behaviour was said to be deliberately motivated at achieving a goal, whether to obtain an object or activity or to avoid it. This goal-directed behaviour was largely in response to conflict, either because the participant was making a request that was not permitted or others were making requests that the person wanted to avoid. Simply, some carers referred to these behaviours as ‘task avoidance’ or ‘to get his own way’.

Limits to Volition

In the majority of cases, an explicit motivation for the behaviour (to obtain or avoid) was not mentioned by the carer. Rather, the trigger was because the person was unable to obtain a request or another person was placing a request upon the person. Commonly, ‘not having demands met’ or the person not obtaining other broad wants and desires such as ‘not getting own way’, ‘requests being denied’, ‘carers refusing demands’, and ‘needs not being met’ were implicated. In some circumstances, there was a sense of urgency with the main issue being that the person could not achieve their want/desire quickly enough. In some cases, carers referred to specific items or activities that the person wanted but could not obtain. Often, these centred on activities such as the person wishing to go out but not being able to, and in other cases it focussed on food and drinks. Other triggers centred on conflicts where a carer wanted the participant to do something but the participant did not want to do it.

The main focus here is the process by which activities can trigger aggression, not the specific type of activity or event, which is covered in the next theme. Another related theme would be the social environment, whereby conflict between person and carer precipitates aggression or the aggression is socially-motivated. Although linked, these themes remain distinct, as all the triggers in the present theme are motivated by something tangible that the person wants, needs, or desires, or wants to avoid.

Specific Activities and Events

Some carers identified very specific events and activities which triggered aggressive behaviour, usually because the person did not want to engage in them. The majority of specific activities related to activities of daily life, especially personal care routines. Similarly, problems around the person taking their medication were reported, as well as attending doctors' or other health appointments. Specific special occasions were also mentioned, particularly Christmas and holidays. The activities and events are likely to trigger due to internal and external environments related to the activity or event. For example, in relation to personal care, some carers suggested that it may be due to proximity and physical contact, which could be regarded as an external, spatial trigger, and that this made the person feel 'interfered with' (an internal emotional trigger). In addition, the Christmas period was commonly implicated, often relating to the sights and sounds of Christmas (external visual and auditory stimuli) as well as increasing excitement (internal emotional state). However, these specific activities/events remain distinct, as they cannot be absorbed fully into the other themes. The carers identified them as separate entities, often only implicitly referring to physical environments having an effect on the internal environments, but not explicitly grounding the activity/event in either. These specific activities/events most likely have a relationship with both internal and external triggers as they are based within the external, but impact on the internal.

Characteristics of ID

Two subthemes emerged that could be grouped together to encompass key features of ID. People with ID have problems with communication and, due to their cognitive deficit, can have problems adapting to certain situations or coping with uncertainty. During the analytic process, it became apparent that carers commonly reported certain situations requiring adaptability due to changes, with the person’s difficulties in coping with this triggering the aggressive behaviour. Furthermore, carers explicitly commented on difficulties with communication, either receptive or expressive, as underpinning aggressive behaviour.

Problems with Adaptability/Uncertainty

The majority of carers described uncertainty or change as precipitating aggressive behaviour. The title for the subheading was chosen as it can be asserted that the person found a situation triggering due to difficulties coping with a change (problems with adaptability) or that a change gave rise to uncertainty. Often referred to were ‘changes in routine’ and some carers went further to explain how changes in routine could affect the participant, in some cases it was specifically ‘unexpected changes to routine’. Additionally, some carers indicated that ‘changes to plans’ or ‘things not meeting...expectations’ could be triggers. Additionally, situations requiring adaptability were mentioned, including ‘having to wait for things’ or ‘queuing’, as well as being ‘impatient’. It can be asserted that such changes could leave the person with a feeling of uncertainty or anxiety and some carer’s highlighted this impact on the internal emotional environment.

There were other triggers that could contribute to a feeling of uncertainty, including ‘inconsistency in management’, ‘hesitancy’ and ‘getting mixed messages from carers.’ New activities or people were identified as being potential triggers, such as ‘strangers’, or ‘new faces, people and places.’ Likewise, others could be aggressive in response to ‘new, additional activities.’ Again, such triggers would require an element of adaptability or could give rise to uncertainty. The majority of triggers within this subtheme related to changes in activities, plans, routines, people, or surroundings. In this way, they are features of both the physical and social external environment and are linked to internal environmental consequences but are united as they implicate a response to change – requiring adaptability. For some it was an unexpected element that was most troublesome. One of the carers suggested this trigger could be mediated by informing/explaining the person of the change.

Problems with Communication

Three main issues relating to communication were described. Some suggested that aggressive behaviour was in response to participants not understanding others or others not understanding them, with the resulting frustration triggering aggressive behaviour. A small number of carers identified the aggressive behaviour as being communication itself, this being a direct result of difficulties in communicating in other ways.

It could be argued that, as both of these features are internal to the person, they would fit into the internal environment theme; however, they remain distinct as they clearly relate to environmental features that are external to the person. These features operate in response to external environments (social and physical) and could be viewed as mediating themes.

Predictability of Behaviour

Many carers commented broadly on the predictability of the behaviour, largely at the start of their response to the question. The comments fell into one of two subthemes, either describing the behaviour as unpredictable or predictable. Forty-one carers suggested that the behaviour of the person they care for was unpredictable, stating that the behaviour can be seemingly ‘random’ and that ‘it is difficult to tell’ what the trigger is. Furthermore, some carers mentioned that the trigger ‘can be anything really’, or could be ‘anything which has upset P’ suggesting that often it was hard to establish clear triggers and that they could vary widely, across situations. One carer also described a distinction between known triggers and behaviour becoming more unpredictable, indicating the person had predictable and unpredictable behaviour. A small minority of carers stated that the behaviour was predictable and suggested that there was always a reason.

Table 38: Quotes to illustrate categories of triggers/motivations.

Theme/ Subtheme	Illustrative quotes
External Environment	
Physical environment	P does not like loud people, the noise will agitate him. People being noisy. P does not like noisy environments. Excessive noise. Loud, unexpected noises, sneezing, coughing. Loud noises will make P jump. P gets verbally aggressive and cross when there are loud, unexpected noises [for example], fireworks. Things on TV, favourite shows like Casualty and Holby City: gruesome things and seeing blood on TV. Violent videos, P would watch them over and over again and get wound up and aggressive himself. P would be aggressive when asked to turn them off. Busyness around the home. P lives in a large group home and it is generally quite busy and noisy; P does not tolerate this very well. Staff changeover; this is because it is a busy time in the house with lots of noise. P does not like crowds or being in groups. P does not like being in busy places, large shopping centres. He will start pacing and shouting as he becomes more distressed in his surroundings. People invading her personal space – P will tend to lash out. P does not like being touched. P does not like too much sensory input and can become overloaded which leads to anxiety and agitation.
Social environment	P will act out to become the centre of attention. P will physically attack other residents to become the centre of attention. P will have temper tantrums to seek company and attention. This is a learnt behaviour as P knows it will get her what she wants – attention from someone. Seems P is always looking for a reaction, for example, his banging will escalate more and more until he has been told to stop it. P likes to get a reaction. To provoke negative reactions in other people, especially other service users. This is part of P exerting his power and authority over people. Being ignored or observing others getting all the attention. Jealousy over other residents getting more attention from staff. Jealousy over other service users especially around staff attention, going out and family visits. P does not see her family very often and she can get jealous when other residents see their family and go to stay with them... this can lead to aggression. When relatives visit, approximately twice a year – exacerbates the problem as P gets excited. Family visits: P can become anxious when he knows his family are due to visit. Going to his parents; P's last severe outburst was related to the build-up in agitation before he went home. Family contact – pre and post; P seems to get upset around family visits,

	could be because she feels rejected. Family rejection can be a key trigger; because of this, P can interpret a lot of things as rejection and this then triggers her aggressive behaviour. Conflicting with his father; they have physical fist fights and tend to wind each other up. Friction with another resident exacerbates the aggression. P is always verbally aggressive towards this other resident but will take out anger on the other residents as well. P clashes with another service user; the other person is very able and verbal as well. They fight over the ‘pecking order’ in the house but do sometimes get on. Two certain staff members – P will be very verbally aggressive when they are on shift. There have been frictions with certain members of staff and the way they supported P. People disagreeing with P – you are better off agreeing with some things. Being reminded he has done something wrong. Being caught out when he has done something wrong. When she is accused of lying. Criticism and being corrected. Other people’s behavioural problems [for example], screaming or anxiety-related behaviours. P does not like to sense other people’s anxiety as it upsets him. Verbal aggression – if other service users are shouting. P gets upset when he hears his parents arguing.
Internal Environment	
Aversive physical states	When P is hungry or thirsty. When poorly. When tired. When P gets too hot. Pain; most of P’s behaviour is related to pain. Pain, hence paracetamol prn [pro re nata/as needed] is often effective as a first line intervention.
Medical conditions	The menopause. PMT [pre-menstrual tension]. UTIs [urinary tract infections]. Hyper or hypo related to diabetes. Constipation and irritable bowel syndrome. Epilepsy. Leading up to a seizure.
Mental health problems	P’s mental health – P will be more irritable and more inclined to shout and slam doors when she is in a hypomanic phase. Paranoia is P’s key trigger; thinking others are talking/spying/staring or looking at him. P can be very violent when his paranoia is bad. Increase in schizophrenia symptoms leads to increase in aggression. When P is depressed, she will be more likely to self-injure. SIB related to depression.
Emotional states	Excitability can lead to an outburst as P gets mixed up with his emotions. P can get anxious when he gets really excited; the increasing emotion can get misinterpreted. The build up, anticipation and excitement of activities can lead to

	aggression. P will become anxious when waiting for an activity. Things that cause anxiety, then agitation, then they can cause aggression. Behaviour is anxiety related – all to do with this. Anxiety; all of P's behaviours are anxiety related. This leads to frustration and then possibly aggression. P will act out when bored. P does not tolerate boredom – P can be aggressive when bored. Boredom – P needs to be kept busy and needs things to look forward to. Feeling he has made a fool of himself. P gets annoyed with himself if he thinks he has made a fool of himself, if someone bumps into him, he will say sorry and be cross with himself. P also gets really upset if he feels like he has caused a fuss. Some days P can be very sensitive. P gets wound up easily and worries over people talking about her.
Expression of Volition	
Goal-directed behaviour	A lot could be learned behaviour as it is very effective for P as he gets what he wants. Can be task avoidance – will shout to get out of doing something. To get his own way. To get out of doing things.
Limits to volition	Usually because P wants something and is unable to get it quickly enough or not at all – demands not being met. Demands must be met immediately, if P cannot find a video he wants, this can be a trigger. Requests being turned down, P not getting what he wants straight away and demands not being met. When P thinks he is going out or wants to go out and is told he is not going out; when other residents get to go out but he does not. P will go and put his coat on and say is he going out but will spit and shout and scream when told he is not. Not going out. A lot of P's behaviours centre around going out – wanting to and not being able to. There are tensions in the evening with P wanting to go out. Aggression tends to occur when demands are not met – usually around drinks. Not getting chocolate when he wants it. Saying 'no' or P being stopped from doing what he wants to do. Encouraging P to do more, especially activities, when he does not want to. Being asked to do something he does not want to – feeling that he is being nagged.
Specific Activities/Events	
Specific activities	Personal care, especially combing P's hair; six out of every seven mornings, P is difficult. P's physical aggression is often around her personal care in the morning. If P feels he is being interfered with – issues around personal care, however, staff have a duty of care to P so this is unavoidable. Encouraging P to take his medications. P will get agitated and aggressive when going to the doctors or dentists. Chiropody visits. Build up to special occasions, visits, appointments, et cetera.
Specific events	Christmas can be very stressful for P; there is often a build up of angry and

	loud behaviour. P has expectations and sees others getting presents and gets jealous. Christmas is a difficult time for P; this can increase her aggressive behaviour. P will throw decorations off the tree et cetera – largely due to the excitement of it all, not intentionally aggressive. Christmas – Christmas holidays; P will get excited and then anxious. Other events have this effect as well, even day trips out. P will repetitively ask what day Christmas is and what is happening.
Characteristics of ID	
Problems with adaptability/uncertainly	Changes to routine, feeling things are out of his control. Changes to routine – P needs to be prepared, for example, if someone is calling at the house, otherwise P would start spitting at them. Unexpected changes in staff – when P not informed of these. When things are late or not going to plan – everything has to have a time, for example, when a phone call is late, P will chunter and bang things et cetera. People not keeping appointments or keeping P waiting; this used to be a problem in the past but is less so now. Uncertainly around change – P needs to know what she is doing every day. Anxiety around feeling like he does not know what will happen next. Changes to routine, this causes anxiety. This is P's key trigger. Everything has to have its own place. Someone moving P's belongings, especially in her room. P does not like change very much [for example], changes to furniture in home whilst she is away at college. Cancelled activities could be a big trigger for P. However, if P is provided with plenty of information, verbally and pictorially, and an alternative activity provided, then P can avoid getting anxious.
Problems with Communication	Feeling like he has not been understood or someone telling P they have not understood him. People not understanding P and therefore leading to frustration and aggression. When P does not understand what others are saying. P's aggression is communicative. To indicate a need – due to communication difficulties; P cannot say what she needs or wants.
Predictability of Behaviour	
Behaviour is unpredictable	Currently, there are often not the obvious triggers that there used to be. The behaviour is becoming more unpredictable. P is having unpredictable mood swings – P can be very happy and content one minute and then he might lash out for example, he hit another service user three times across the face. P can be very unpredictable. Outbursts are often unprecedented. P has random outbursts. Often [you] cannot find a trigger. Really varied, hard to tell what the trigger is. Sometimes it is not always clear what sparks the behaviour.
Behaviour is predictable	P is not usually aggressive for no reason. When P has been unhappy and angry, there is always a reason.

Relationships between Triggers and Motivations

Figure 9: Schematic map of triggers and motivations for aggressive behaviour identified by the carers

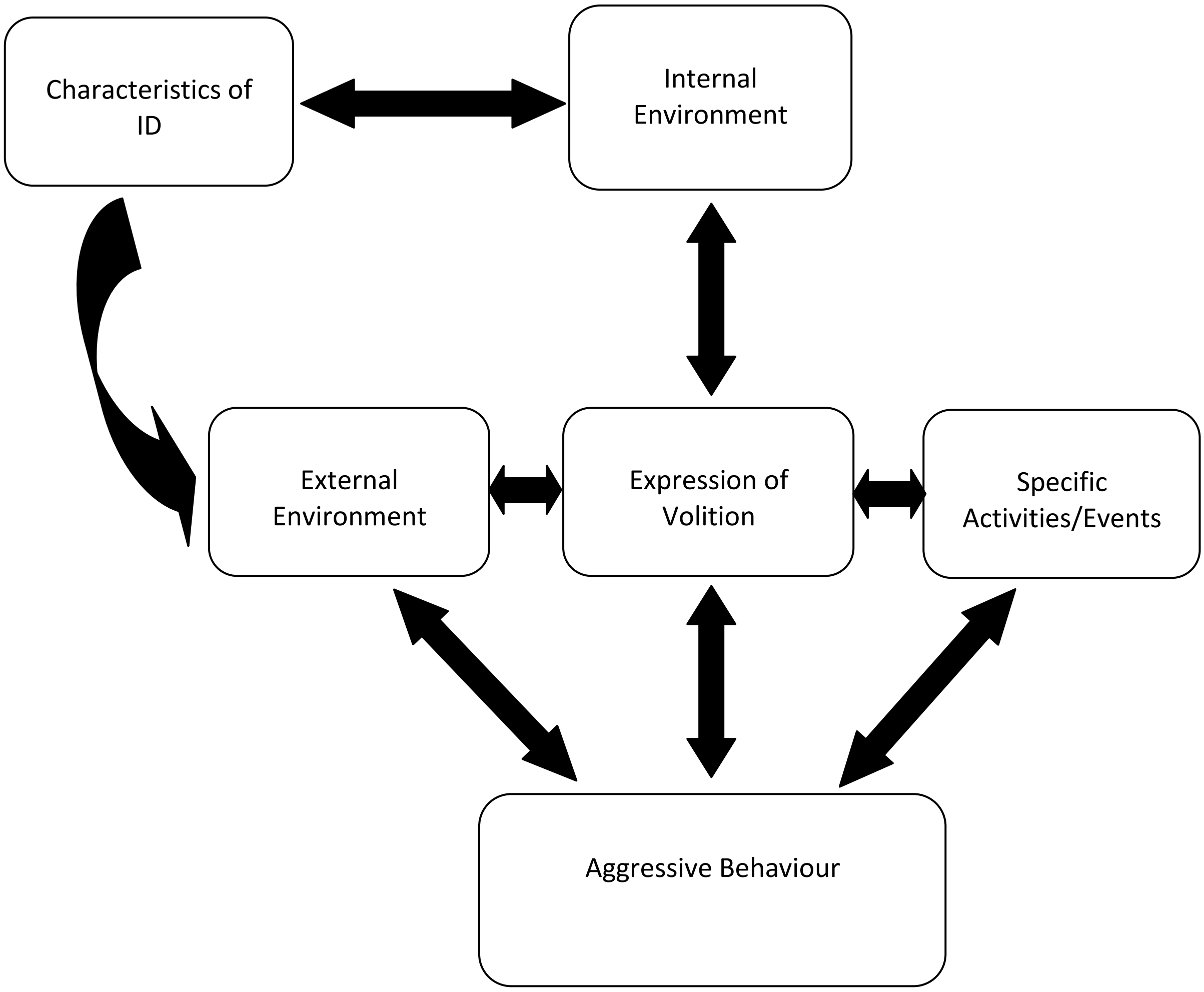


Figure 9 provides a schematic map of the themes to present how the themes may inter-relate, as described, there is a lot of overlap between the categories. The middle three categories can be considered as all relating to aspects of the external environment, either being specific aspects of that environment or relating to the person's interaction with aspects of that environment and carers commonly identified these factors. Such variables could be considered as discriminative stimuli and external setting events as outlined in Figure 8. It is posited that features of the person's internal environment influences their response to these factors and vice versa, similar to the notion of establishing operations in Figure 8. However, features of the internal environment may also act as internal setting events or discriminative stimuli. All these factors therefore contribute to aggressive behaviour, however, the importance of each factor will vary across individuals, times and environments, as indicated by the varied responses by carers.

Discussion

The carers interviewed were aware of an array of varied triggers and motivations suggesting that there are a wide range of variables that may elicit aggressive behaviour (see Appendix 21 for a summary of specific triggers identified, arranged under the headings derived from the thematic analysis). Triggers for aggressive behaviour vary across and within individuals and may be subject to change over time and contexts (Romanczyk et al, 1992). The triggers were organised into six distinct but related categories namely, external environment, internal environment, expression of volition, specific activities/events, characteristics of ID and predictability of behaviour. These six categories, each with subcategories, accounted for almost all of the individual variables that were identified, suggesting that, whilst specific triggers/motivations are often idiosyncratic, they can be organised into a small number of more generic trigger types and subtypes. Furthermore, some individual triggers or motivations were commonly cited suggesting that these may play a role for a majority of individuals with ID who exhibit aggressive behaviour.

As carers are often relied upon to inform functional assessments (Rojahn et al, 2012; Hastings & Brown, 2000), it appears that they may be reliable sources of information and are aware of a wide range of contextual variables that precipitate aggressive behaviour. However, the carers interviewed may have received information from clinicians as all were in contact with specialist health services and the paid carers may have received some behavioural training so this result is perhaps not unexpected. Despite this, knowledge varied and the results may highlight a training need for carers, as discussed later.

Categories of Contextual Variables in Existing Checklists

There are similarities in the categories derived from the thematic analysis and those from the CAIPB (McAtee et al, 2004), indicating that carers' knowledge of contextual variables broadly fits with what is known by experts in the field. Both have categories relating to the social environment and the physical environment, however, the present analysis grouped these two variables under the main theme of external environment, as previously suggested in the theoretical literature (Bijou & Baer, 1978). Furthermore, both the CAIPB and the present analyses derived a category relating to features of the internal environment, including illness and physiological states. Finally, both have a category predominantly relating to tasks and activities, including items relating to requests/instructional variables and volition, however, the present analysis also had a separate category for specific tasks and activities. This theme was developed late in the analysis from inspection of text that was not coded and might comprise a useful checklist of potentially triggering activities and events. Two further categories, not included in the CAIPB were derived from the carer's accounts and are perhaps useful in understanding carer's perceptions, namely, predictability of behaviour and characteristics of ID; these will be discussed in more detail later.

McAtee and colleagues (2004) administered the CAIPB with 40 care workers who completed the scale about 20 individuals predominantly with severe or profound ID. Commonly cited contextual variables eliciting problem behaviour related to hunger/thirst, illness/pain, waiting for things, failure to have requests met and feeling that others are too close or far away. Such triggers were also commonly cited in the present study, however, aversive physical states were less commonly cited. This may be explained by differences in sampling (the present study included adults with all levels of ID residing in the community (including family homes) and displaying specifically aggressive behaviour). Embregts and colleagues (2009a) conducted a study with 87 children and adults with borderline and mild ID who exhibited outwardly-directed aggressive behaviour in residential facilities. Aggressive behaviour was most commonly precipitated by ‘social/cultural’ or ‘tasks/activity’ variables with ‘biological’ or ‘physical variables’ less likely to elicit aggressive behaviour. Analysis of the subcategories indicated that ‘negative interactions’, ‘factors related to tasks’, and ‘factors related to daily routines’ were most likely to elicit aggressive behaviour. Similar results were observed in this study whereby the social environment was the most commonly mentioned subcategory followed by limits to volition. The results of these studies may indicate that contextual variables differ for those with milder or more severe ID.

Comparisons can also be made between the Setting Events Checklist (McGill et al, 2005) and the present analysis with both including aspects relating to the physical setting (relates to physical environment), activities (relates to expression of volition and specific activities and events), time of year (relates to specific events), social context (relates to social environment), personal context (relates to internal environment) and presence of certain other staff or service users (relates to social environment). There was little emphasis in this study on temporal variables such as time of day or week and weather conditions and McGill and colleagues (2005) did not further consider these categories in their study as they were rarely endorsed by carers. Of the setting events that were identified by a majority of carers, factors relating to the personal context (‘when tense or anxious’, ‘in a bad mood’, ‘when depressed or sad’), social context (‘in a crowded room’, ‘when there is a lot of noise’), and activities (‘doing tasks they find difficult’, ‘doing nothing’, and waiting for an activity) were commonly cited (McGill et al, 2005). Similarities can be observed with the present analysis (however, direct comparisons are difficult due to style of reporting) in which carers commonly endorsed similar categories, especially, in relation to emotional states. However, greater emphasis was placed on the social environment, especially interactions between the individual and others. Again, this may be due to the aforementioned sampling and methodological differences with the study by McGill and colleagues (2005) only including 22 individuals with predominantly severe ID in residential facilities.

It is of note that McGill and colleagues (2005) include features such as noisy environments in their ‘social context’ category which is in contrast to the present analysis that grouped noisy environments in the physical environment subcategory. Whilst many of the specific triggers related to noise made by other people and so are related to the social environment, some noises were not generated by others and are therefore aspects of the physical environment, this highlights the potential overlap between categories and how exploration of the type of noise is important. Furthermore, differences can be observed in the ‘activities’ category that combines features of the limits to volition and emotional states subcategories, again highlighting the potential for overlap. As indicated in Figure 8, it is likely that features of the external environment impact on the internal environment.

Whilst the CAIPB and Setting Events Checklist have been applied to some individuals with ID, it may not be applicable in the present context as the literature on which they are based is mainly with children, they include problem/challenging behaviour with no focus on aggressive behaviour, they have only been used by paid care staff and only relate to people in residential settings. The benefit of the present analysis is therefore the inclusion of both family and paid carers and people with ID from a range of residential settings so the results may be more representative of a wider range of individuals.

Functions and Motivations for Aggressive Behaviour

As would be anticipated due to the question posed to carers, carers provided a combination of both contextual triggers and underlying motivations for behaviours. However, despite asking about motivations, rarely were functions explicitly identified, other than in relation to attention. Many triggers can be mapped onto functions for aggressive behaviour, however, this may take professional (psychological) experience and insight that carers may not possess and would also go beyond the data-driven analytic approach used in the present analyses. Understanding behaviour in terms of the functions it serves for the individual offers explanations of the contextual control of the behaviour, in other words, how contextual features provide a motivational function for behaviour by ‘establishing the reinforcing potential of previously neutral stimuli’ (O’Reilly et al, 2012; Emerson & Einfeld, 2011, p. 42). Whilst there are many commonalities between commonly-cited functions and the present themes, it is not possible to map all the contextual variables onto a function without a significant amount of interpretation. This supports the notion that carers may find it difficult to locate a function for behaviour and identification of additional contextual variables may be more accessible.

There are a variety of functional assessment instruments for use with carers. Commonly used instruments include the Motivation Assessment Scale (Durrand & Crimmins, 1988), QABF Scale (Matson & Vollmer, 1995), Functional Analysis Interview (O’Neil et al, 1990), and Antecedent-Behaviour-Consequence (A-B-C) Charts (Tustin, 1993). The QABF scale currently has the most empirical support with well-established psychometric properties and good validity, including concurrent validity with experimental functional analysis methods (Matson et al, 2012a; Zaja et al, 2011; Embregts et al, 2009b; Singh et al, 2009; Hall, 2005; Paclawskyj et al, 2001; Matson et al, 1996; Matson & Vollmer, 1995). The QABF is used to rate maintaining factors for a specific behaviour against 25 items under five headings. This five-factor structure has been consistently demonstrated (Singh et al, 2009) and incorporates the subheadings Attention, Escape, Non-social, Physical, and Tangible. The QABF is administered by professionals with background and training in applied behaviour analysis (Matson et al, 2012a), is not for independent use by carers, has not been validated for use with family carers or community-based adults and much of the literature is from residential care contexts (Freeman et al, 2007).

Reinforcing actions relating to attention tend to comprise verbal reprimand as well as more positive verbal statements and physical contact (Matson et al, 2011). This mirrors the triggers identified within the social environment theme whereby both positive and negative aspects of attention were identified as underlying the behaviour. Carers commonly implicated attention as a clear motivation for aggressive behaviour which compliments some existing literature (McClean & Grey, 2012; Embregts et al, 2009b). For example, Matson and colleagues (2011) review 173 functional assessment papers and conclude the most commonly reported functions are attention (in 88 studies) and escape (in 72 studies). However, carers also mentioned other issues that were not clearly examples of attention-controlled motivation and may represent reactions to the social climate such as presence of certain staff members or service users, conflicts with others, witnessing conflicts, lack of family contact, or contact with family. Exploration of these contexts suggests that much behaviour could indeed be motivated by access to attention, either positive or negative, however, witnessing the conflicts of others or a lack of family contact may represent more distal contextual factors that are not necessarily related to a function.

The escape subscale of the QABF relates to the limits to volition subtheme and carers commonly identified that behaviour may be in response to the person being encouraged to do something they did not want to do. Previous studies have suggested that aggression is most commonly maintained by escape (Rojahn et al, 2012; Matson et al, 2011; Matson & Boisjoli, 2007; Hanley et al, 2003; Menckel et al, 2000; Applegate et al, 1999; Carr et al, 1999; Iwata et al, 1994b). This subtheme also includes aspects of the tangible function as it can be interpreted that as people were said to display aggressive behaviour when they are not able to fulfil their desires, their behaviour may be with the aim of achieving that desire, this would represent goal–directed behaviour, the other subtheme in the expression of volition main theme. However, very few carers explicitly identified goal-directed behaviour in relation to trying to achieve something (tangible) or avoid something (escape), rather, they could identify the contextual variable such as demands not being met or requests being made of the person. Furthermore, carers rarely considered that the person could be trying to access tangible items outside of activities, food or drink. The specific activities and events theme may also be interpreted as being maintained by escape functions, however, the data from carers did not support their inclusion in the volition category as carers did not provide any qualification. Aggressive behaviour triggered by specific activities and events could be considered as avoidance behaviour in that there may be no obvious escape consequence (Emerson & Einfeld, 2011). The emergence of issues around expression of volition as a key theme highlights the reduced autonomy in people with ID and the reliance on carers for access to activities and items.

Matson and colleagues (2011) suggest that rarely is a physical function considered in the literature, however, carers tend to most reliably identify physical items on the QABF (Matson & Wilkins, 2009). The QABF assesses physical functions in relation to pain, discomfort, hunger, physical problems and not feeling well. This is similar to the internal environment theme identified in the present analysis. However, the internal environment theme also includes issues relating to emotional states which are not covered by the QABF but were identified by 58% of carers. McGill and colleagues (2005) also report on the tendency for functional assessment to neglect personal setting events, especially emotional states despite them accounting for a relatively large amount of variance in behaviour. Carers often implicated underlying anxiety, agitation and stress which may not relate to a function but represent personal contextual variables with aggressive behaviour serving to express this emotional state or the emotional state lowering the tolerance of certain environmental stimuli. Indeed, Smith and Iwata (1997) comment on this discrepancy and suggest that establishing operations include emotional variables, deprivation and aversive stimulation as these are not always ‘correlated with the availability of response-contingent escape, which is a requirement for discriminative control’ (p. 348). For example, pain is not necessarily contingent on the availability of removal of pain and behaviours may be equally maintained by positive and negative reinforcement with the carer providing or withdrawing attention/activities when aggressive behaviour is expressed contingent on an underlying emotional state. Carers commented that boredom may trigger aggressive behaviour, this may relate to the non-social reinforcement category of the QABF whereby aggressive behaviour may be self-stimulatory, in the absence of attention-based reinforcement.

Carers were not really aware of this potential function and may require help to understand such behavioural determinants, which compliments other research (Embregts et al, 2009b).

The theme of physical environment includes ecological variables relating to the auditory, visual and spatial context that do not appear to be covered by the QABF, yet have been often cited but rarely studied (McGill et al, 2005; Durrand, 1990). It could be asserted that the escape function was activated in response to many of these triggers, however, this relationship is not necessarily evident from the carers' accounts. For example, aggressive behaviour in response to unexpected or loud noises or lights may relate to disturbances in sensory processing (a personal contextual variable) and the behaviour may therefore not be aimed at escaping these stimuli but rather in modulating their impact on the individual. Furthermore, aspects of the characteristics of ID category, which includes personal contextual variables, are not commonly considered in functional models of behaviour despite a high rate of occurrence in carer's reports. As Langthorne and colleagues (2007) suggest, 'a functional analysis based on environmental (challenging environments) and biological (challenging needs) motivating operations provides a more parsimonious ... account of challenging behaviour' (p. 466).

The Social Environment – Implications for Carers

The present study compliments existing literature suggesting that most aggressive behaviours are socially-motivated (e.g. Applegate et al, 1999; Iwata et al, 1994b; Carr & Durrand, 1985; Iwata et al, 1982) with seventy-five per cent of carers identifying a social trigger. Carers are a key feature of the social environment and therefore play a role in shaping aggressive behaviour. Carers may shape behaviour through habituation, 'getting used to' the behaviour and only responding to more and more intense or complex forms over time, thus differentially reinforcing aspects of the behaviour already exhibited by the individual (Emerson & Einfeld, 2011; Oliver, 1993; Guess & Carr, 1991). Equally, carers often seek to avoid aggressive behaviour, avoiding interactions with those whose behaviour is maintained by negative social reinforcement and increasing interaction with those whose behaviour is maintained by positive social reinforcement, providing further reinforcement of the behaviours (Hasting & Brown, 2000; Oliver, 1995; Hall & Oliver, 1992; Taylor & Carr, 1993; Carr et al, 1991). Interpersonal difficulties between care staff and people with ID (including emotional responses to aggressive behaviours and expressed negative emotion towards clients) are associated with staff emotional exhaustion, depersonalisation/cynicism, a feeling of lack of achievement and productivity, and burnout (Rose et al, 2004; Mitchell & Hastings, 2001).

Training for Carers – Improving Knowledge, Attributions and Responses

Carers demonstrated some knowledge about triggers and motivations, however, knowledge varied with some carers struggling to identify any triggers and forty-one per cent of carers stating that aggressive behaviour was unpredictable. Some carers were aware of the role of others in the environment, however, few explicitly reflected on how their behaviour may influence aggressive behaviour. Furthermore, only 16% of carers mentioned issues around communication despite much aggressive behaviour being considered to be communicative or as a result of limited verbal communication (Matson et al, 2011; Singh et al, 2009; Hastings & Brown, 2000; Bott et al, 1997). Carers also spoke about how problems with adaptability/uncertainty precipitated aggressive behaviour with some emphasis towards the person’s impairments (for example, being impatient, an internal attribution of control) rather than environmental constraints. Studies investigating the attribution model (Weiner et al, 2006; Dagnan et al, 2013) have demonstrated that internal judgements about the control individuals have over challenging behaviours predicts placement breakdown and staff response, with carers more likely to help where the behaviour is interpreted as out of the control of the person (Cudré-Maroux, 2011; Phillips & Rose, 2010).

Carers may benefit from training and information about potential triggers to help them think more about environmental conditions and their own role in the environment. Training could work on two levels: an educative/knowledge level and an attitudinal/attributional level. The limited research with paid carers suggests low levels of behavioural/mental health knowledge and training (Allen et al, 2005; Edelstein & Glenwick, 2001; Quigley et al, 2001) and it can be asserted that informal family carers have less knowledge and training. Behavioural training for care workers has been shown to improve knowledge, attitudes, attributions and understanding of behaviours (Rose et al, 2013c; Costello et al, 2007; Lowe et al, 2007b; McGill et al, 2007), improve sense of empowerment, self-efficacy and empathy (Hutchinson et al, 2012) and has resulted in reduced levels of aggressive behaviour and improved behavioural support plans developed by services (McClean & Grey, 2012; Dowey et al, 2007; McClean et al, 2005). Improvements in behaviour may relate to a reduction in attributions that the person is in control of their behaviour by better understanding of factors that are beyond the person's control thus improving helping behaviour. Studies have shown that beliefs about controllability are subject to change with staff training (Dilworth et al, 2011; Kalsy et al, 2007). Little research has investigated issues for family carers (Allen, 1999) however, research has indicated that parents who maintain higher levels of perceived control over their situation experience lower levels of stress (Hill & Rose, 2009).

Interventions for Aggressive Behaviour based on Assessment of Contextual Variables and Functions

The identification and modification of contextual variables can be useful in the prevention of future aggressive behaviours (Embregts et al, 2009a). Three strategies for intervention can be employed, namely avoidance of contexts that trigger aggressive behaviour, altering the context, or teaching coping skills relevant to the context (Carr et al, 2008). Studies have demonstrated that interventions based on the CAIPB to design 'avoid-mitigate-cope' strategies have been shown to be effective (Blakeley-Smith et al, 2006; Cale et al, 2006, cited in Carr et al, 2008). McClean and colleagues (2007) demonstrated the benefits of a similar multi-element approach based on positive behavioural support. However, they note that direct care staff were given intensive support to develop and deliver the intervention, again highlighting the need for training and information provision.

Checklists for use by Carers

The present results may be used to develop an inventory to help carers identify contextual variables that trigger aggressive behaviour (see Appendix 21 for a draft outline of the proposed checklist). The detailed description of triggers for behaviour has been identified as a key component of quality positive behaviour support plans while understanding the function of behaviour was less frequently endorsed, possibly owing to its complexities (McVilly et al, 2013). The quality of positive behavioural support plans has been shown to affect outcome (Webber et al, 2012). The checklist may be a useful self-reflective tool to help carers think more about the role of the environment and themselves, to think about ways to avoid or minimise the impact of triggers and to develop behavioural support plans, especially for carers who have not known the person long and who therefore may not be able to spontaneously identify as many contextual variables (McAtee et al, 2004). Such plans, developed by direct carers rather than other professionals may have better 'contextual fit' being developed in the environments in which they are to be implemented (McClean et al, 2005). The checklist should be accessible to carers as the development was based on their knowledge and phrasing, this is a novel approach, especially owing to the inclusion of family carers.

The checklist could be completed in advance of a clinic appointment to help inform more detailed functional assessment (McAtee et al, 2004). Owing to the difficulties with experimental functional analysis, in clinical practice, a descriptive analysis is most commonly used, often informed by interviews with carers (Desrochers et al, 1997) and checklists have been shown to elicit more comprehensive accounts of behaviour from carers than open ended questioning (Einfeld and Tonge, 2002). This may also have the benefit of improving carer investment in the intervention and subsequent fidelity to the behavioural plan (Hieneman & Dunlap, 2000). Furthermore, a checklist may be useful in a research context where it is difficult to perform a full functional assessment due to resource constraints. This would allow researchers to investigate the relationships between specific contextual variables and topography of aggressive behaviour in a systematic fashion. Further work could seek to develop the checklist and assess its psychometric properties (reliability and validity), following the methods outlined in Appendix 15.

Conclusions

Existing attempts to categorise contextual variables tend to generate an item pool from existing literature; do not use qualitative methods to formally structure the items into categories, relying on expert opinion; and use small sample sizes and residential care settings. The present chapter took a different approach to identify and organise contextual variables and motivations for aggressive behaviour of adults with ID. The categories were based on data from a large sample and the emergent themes accounted for almost all the individual triggers identified by the carers thus increasing the generalisability of the results and suggesting the proposed model is comprehensive.

Existing research suggests that triggers may be idiosyncratic, however, there appears to be some commonalities with some specific triggers regularly mentioned. Indeed, almost all carers mentioned some form of external environmental trigger for aggressive behaviour. This warrants further research to investigate factors such as noise and crowded places in more detail. Little research has sought to investigate the associations between topography of aggressive behaviour and specific features of the environment which could be a target for future research. In this way, the triggers and motivations could be viewed as potential risk factors.

It is important to note that the trigger/motivation categories identified may not account for the ‘multiplicity of independent (and partially independent) pathways that may lead to [aggressive] behaviour’ (Emerson & Einfeld, 2011, p. 59). It is unlikely that a single model could ever account for the heterogeneous, transient, temporal aspects of aggressive behaviour. The model presented here reflects the knowledge of carers and suggests that, as a group, carers were aware of a wide range of variables that have previously been cited in the literature. The ‘bottom up’ approach led to a different structuring of variables which may be more reflective of carer’s understanding and may indicate that carers have difficulty in defining a function and behavioural reinforcers for behaviours without assistance. The data from carers could be used to develop a checklist, for independent use by carers to help them reflect on potential causes of behaviour. Clinicians may also want to dedicate time to discussion with carers when developing positive behaviour support plans to harness the knowledge of carers and to also spend time explaining hypotheses about functions.

CHAPTER 7: SUMMARY WITH COMBINED LIMITATIONS AND RECOMMEDATIONS FOR FUTURE RESEARCH

This study examined aggressive behaviour over the course of a year among a clinical cohort of adults with ID, taking account of the manifestation of the behaviour over time, personal and environmental risk factors, and a range of related variables. The study is not epidemiological, instead, it represents clinical research set in real health service settings (McCarthy et al, 2010). The study was explorative and holistic and sought to examine a wide range of variables implicated by both behavioural and biological/medical approaches to address what Hemmings and colleagues (2013) call a potential 'weakening rather than fostering' of links between approaches (p. 147). Few studies have investigated aggressive behaviour longitudinally, especially over a short time period with multiple data collection points. The present study therefore goes some way to providing evidence of temporal relationships with aggressive behaviour. The author is not aware of any other studies that have investigated independent risk factors for aggressive behaviour over time in a community-based clinic sample. Furthermore, few studies consider contextual risk factors and none have studied such variables in a sample, including those who live with family.

Around 46% of adults who were in contact with specialist health services displayed aggressive behaviour according to the definition outlined in the eligibility criteria. Most individuals who exhibit aggressive behaviour tend to show multiple forms, most commonly, three of the four types. Despite this, behaviours tended to be in the mild-moderate range, with verbal aggression most common, suggesting that clinical support is needed even for less severe behaviours. This result is not unexpected given that participants were recruited from CLDTs. It is likely that those with more severe aggressive behaviour may be hospitalised. However, the results of this study provide a profile of the behaviour of a clinical cohort, and as such may inform service planning and delivery.

Severity of all three forms of outwardly-directed aggressive behaviour (verbal aggression, property destruction, and physical aggression to others) were related, however, despite almost all those who exhibit SIB also exhibiting outwardly-directed aggression, severity of SIB was unrelated. All those who exhibited physical aggression to others exhibited other forms of aggressive behaviour, perhaps due to an escalation effect in those who exhibit more severe forms of behaviour. Conversely, verbal aggression was most likely to be exhibited in isolation (in 17% of participants). Around 12% exhibited all forms of behaviour and only 5% exhibited SIB alone. Therefore, SIB demonstrates independence in terms of severity but most of those who exhibit SIB also display outwardly-directed aggression. Different profiles of aggressive behaviour may therefore exist, complimenting previous research which identified similar profiles among adults with mild or moderate ID (Crocker et al, 2007). Crocker and colleagues (2007) devised six distinct profiles including an ‘acting out’ group who exhibit mild forms of verbal or physical aggression towards others or property (23%), a ‘self-mutilation’ group reflecting individuals who display mostly SIB at much higher levels of severity than the total sample (6.4%), and an ‘aggressive’ group who display all forms of aggressive behaviour, including SIB and physical aggression to others at milder levels and all levels of severity of verbal and property destruction (18.6%).

Aggressive behaviours tended to emerge in childhood, suggesting long-standing behaviours and highlighting the importance of early identification and intervention. However, aggressive behaviour improved over the 12-month follow-up with over 17% of the cohort demonstrating both a clinically significant and reliable improvement. This suggests that, whilst presence of behaviour may be persistent over the long-term, severity of behaviour may fluctuate over the short-term, so behaviour may be episodic. The strength of this study is therefore the short-term longitudinal design with multiple data collection points. This finding has service implications as it may be important to inform carers about the enduring, but potentially fluctuating, nature of aggressive behaviour with the potential for fluctuations possibly providing a source of optimism. Improvement in behaviour may be as a result of effective interventions and support provided by CLDTs. Further research could seek to investigate the nature of specialist health service provision for this group and to identify whether certain features of service provision tend to lead to better outcomes. Currently, there is very little service-related research in the field. Further research could also continue to measure aggressive behaviour at six month intervals to investigate whether relapse occurs to confirm the conclusion that behaviour is episodic. Clinicians may want to emphasise the potential for relapse when discharging patients and consider a relapse plan and early warning signs and communicate these to carers and patients so that, even when the behaviour is stable, there is plan for if the behaviour worsens in the future.

Cross-sectionally, increased severity of aggressive behaviour was associated with increased carer's concerns and family carer burden and decreased family carer uplift, confirming previous research. However, only carer concerns demonstrated the same trajectory of improvement over time along with aggressive behaviour. Generally, family carer uplift was high suggesting that, despite the challenges faced by caring for a family member who exhibits aggressive behaviour, the experience is also positive. Quality of life amongst the participants was most associated with lethargy and social withdrawal and was only weakly related to one measure of severity of aggression. However, whilst lethargy and social withdrawal improved over the follow-up, quality of life remained stable. A longer follow-up may be required for changes in quality of life to be noted as it may take some time for activities to increase and for relationships with others that have been compromised by the aggressive behaviour to improve. Furthermore, it may be important to consider the social interactions of those who exhibit aggressive behaviour and attempt to increase participation in activities to improve quality of life.

The development of a risk profile for aggressive behaviour may assist in the identification and adequate treatment of individuals and the provision of support to those around them. However, few personal, relatively stable risk factors were associated with topography of aggressive behaviour. This is encouraging, given that such variables are often not amenable to change including factors such as age or type of residence. Despite this, a relatively robust model for predicting the severity of aggression was developed, including predominantly behavioural and psychiatric variables. The model based on T1 variables accounted for around 50% of variance in severity of aggressive behaviour at T2 and T3. Only previous severity of aggressive behaviour independently predicted later severity, suggesting a degree of consistency in behaviour over time. Other risk factors were identified, however, they were not individual predictors indicating overlap between these variables. For example, ASD and stereotypic behaviour both predicted severity of aggression in the group-specific models, however, their shared variance resulted in loss of independent predictive utility when combined. These findings perhaps suggest that future research should shift focus from attempting to identify independent risk factors and instead look at the interactions and overlap between factors (Kraemer et al, 2001).

The behaviour-specific models tended to lose predictive power over time, no longer predicting presence of the behaviour by T3. It may therefore be difficult to predict future presence of behaviour. Indeed, in the severity models, around 50% of variance was still unaccounted for, which implicates residual unmeasured variables (Vandenbroucke et al, 2007). Contextual features may account for some of this variance and the carers interviewed identified a wide variety of contextual triggers for aggressive behaviour both across and within individuals. These findings have several implications. It may be difficult to develop a robust risk profile for aggressive behaviour owing to the complex interactions between varying contextual, personal and environmental variables. However, carers should be provided with information and tools to assist in identifying contextual factors related to aggressive behaviour in order to help them develop and implement behavioural support plans. Indeed, a large proportion of carers felt that the aggressive behaviour was ‘unpredictable’ further implicating a need for resources and information. Training and intervention tools are currently available, however, these are aimed at clinicians and professionals and not direct care providers (Hastings & Brown, 2000). A checklist based on the triggers identified by carers may be useful as a self-reflective tool for carers to help them better understand the reasons for behaviour and to develop management strategies.

Severity of behaviours relating to hyperactivity/non-compliance was independently related to severity of aggression, presence of property destruction and presence of physical aggression to others. Such behaviours are related to ADHD, so perhaps this reflects underlying and undiagnosed ADHD in the sample (carer's were aware of a diagnosis of ADHD in only four participants). However, it could also represent ADHD-type symptoms in the absence of a clinical condition and therefore a thorough assessment of other problem behaviour, as well as aggressive behaviour, should take place. Furthermore, interventions for ADHD may be of use to improve aggressive behaviour especially those which seek to improve functional skills such as impulse control.

Individual behaviours included in the hyperactivity/non-compliance subscale of the ABC relate to the external, predominantly social, environment as the person reacts in a defiant, disruptive way. This compliments findings from the analysis of contextual variables identified by carers, whereby the most commonly cited subthemes were social environment (by 75%) and limits to volition (by 65%). Often, aggressive behaviour was in response to a person not being able to achieve their wants and desires. People with ID often rely on carers for access to items and activities, so carers should be aware of their potential impact on the person and their behaviour. Whilst it may not be feasible or practical to offer or remove the activity or item that the person desires or wishes to avoid, especially in social care contexts, care should be taken in the response and further research could investigate the most acceptable ways for carers to respond to minimise the likelihood of aggressive behaviour.

Complimenting previous research, those with severe-profound ID were more likely to exhibit SIB. As ID was measured using a functional and adaptive behaviour checklist this may indicate a relationship with reduced functional/adaptive behaviour, perhaps highlighting a need for skills training for those who self-injure. This finding may also implicate a shared biological aetiology with ID, leading to neuro-developmental sequelae and a reduced capacity to cope with contextual features.

Limitations

The recruitment rate to the study appears low, however, the sample was largely representative of clinic-based samples of adults with ID and aggressive behaviour so the results may be generalisable. The rate of attrition was moderate and there were incomplete data sets due to difficulties completing all the scales in some interviews. Missing data is common in observational research (Vandenbroucke et al, 2007) and various methods for dealing with missing data were considered, however, it could not be assumed that data were missing at random and therefore it was not appropriate to impute data using traditional methods. Despite the attrition rate, the sample at T3 remained largely representative of all those recruited. Owing to the holistic measurement of variables, the study was perhaps too ambitious in data collection and underestimated how much carers wanted to discuss the issues they faced. Researchers in the field should consider these factors when planning studies. Qualitative studies may provide a useful method to explore the experiences of carers and may help elucidate some of the processes alluded to by the quantitative analyses performed in this study.

The majority of the sample were recruited from psychiatrist-led clinics representing sampling bias. However, this may be representative of service provision nationwide as, in some areas, psychological provision is still in short supply. For example, at the time of recruitment, one of the sites had access to a clinical psychology for just half a day a week. Furthermore, as participants were ongoing patients and not specifically new referrals, it is more likely that they exhibited enduring aggressive behaviour.

There may also have been over-representation of those living with family in the present study. However, this is probably a positive feature of the study as much research has tended to focus on those in community care homes.

The present study did not recruit a comparison group without aggressive behaviour. Such a control group would have allowed the comparison of the profile of those with to those without aggressive behaviour. Much existing research has taken this epidemiological approach to identify risk factors for prevalence of aggression, however, varied results have been reported. Therefore, the present study sought to utilise a health research design to investigate predictors within a sample who all exhibit aggressive behaviour. This approach allowed the more detailed investigation of topography of such behaviour. Owing to resource limitations, recruiting only one group ensured adequate statistical power to the regression analyses and allowed the modelling of severity of aggressive behaviour, including a wide range of putative risk factors amongst a clinical sample rather than a population-based sample. This was especially pertinent given the known difficulties recruiting to studies in the field, longitudinal design and potential for attrition. However, it should be noted that the risk factors identified in the present study do not represent risk factors for prevalence of aggressive behaviour amongst all adults with ID, rather, they are risk factors for topography of aggressive behaviour amongst those who exhibit aggressive behaviour.

All measures were informant-rated, proxy measures, this places limits on the reliability of ratings, introducing inherent measurement error, however, all measures used had proven reliability and validity. This issue could be addressed by researcher observations of aggressive behaviours. However, this approach is resource intensive as behaviours may not occur frequently and therefore might not be exhibited during the observation period. The ABC-I was used as a measure for aggressive behaviour. This is a widely used but broad measure that incorporates aggressive behaviour (including SIB), mood symptoms and temper tantrums. Therefore, some associations may have been obscured. However, the ABC has a proven factor structure and validity suggesting that the ABC-I measures a single underlying construct indicative of aggressive behaviour. Given the different risk factor profile for SIB in the present study and the predominance of research seeking risk factors for prevalence of behaviour, future studies should seek to identify associations with severity of specific forms of aggressive behaviour. Whilst specific forms were investigated, they were only investigated in relation to presence/absence. Further work should therefore develop robust measures for severity of individual types of aggressive behaviour and use these to identify risk factors.

The results highlight that aggressive behaviours are likely to be the result of a ‘complex, multiple causal chain that may involve genetic, environmental, social and biological risk factors, the effects of which cannot be understood in isolation’ (Kraemer et al, 2001). Predisposing, precipitating and perpetuating risk factors combine to elicit behaviour. A thorough assessment that includes psychiatric, behavioural and functional assessment is required to lead to a multi-modal treatment plan (Deb et al, 2009; Unwin & Deb, 2010). Such practice is currently in use, however, it is resource-intensive and therefore is not commonly available. Therefore, a contextual approach may provide an accessible way for carers to assess and intervene in behaviour. Clinical assessments should include consideration of anxiety disorder, ASD, stereotypic behaviour, hyperactivity/non-compliance and underlying ADHD, features of the social and physical environment, reactions to limits to volition, emotional states and problems with adaptability and uncertainty. A goal for research could be to combine these factors to produce an algorithm to calculate risk of developing aggressive behaviour, which could be used to aid early identification and intervention. Early intervention in prototype aggressive behaviour may in turn, impede the development of enduring aggressive behaviours.

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APPENDICES

APPENDIX 1: BRIEF REVIEW OF MANAGEMENT STRATEGIES/INTERVENTIONS FOR AGGRESSIVE BEHAVIOUR

A broad range of management strategies and interventions are currently used with people with ID who exhibit aggressive behaviour, ranging from the use of medication to environmental and behavioural modification (see Hemmings et al, 2013 and Deb, 2013 for an up to date review on this subject). Attention has been paid to determining the efficacy of these interventions in the research literature with varying results. It has been asserted that the varying results may be due, at least in part, to the types of problem or aggressive behaviours studied (Benson & Brooks, 2008). For example, a small retrospective study indicates that atypical antipsychotic medication does not reduce total aggressive acts, although a reduction was observed for aggression when SIB was excluded (Ruedrich et al, 2008).

A series of comprehensive systematic reviews conducted as part of the development of a UK-based national guideline on the use of medication in adults with ID and problem behaviour, identified a paucity of good quality research literature demonstrating the effectiveness of medication (Unwin & Deb, 2011; Deb et al, 2008; Deb & Unwin, 2007b; Deb et al, 2007; Sohanpal et al, 2007). The authors of these reviews conclude that there is currently equivocal evidence in relation to most medication, with only the use of Risperidone in children with ID and/or developmental disorders being supported by good quality evidence. A recent randomised controlled trial of antipsychotics for challenging behaviour did not demonstrate effectiveness of medication (Tyrer et al, 2008). Despite this, psychotropic medications are commonly prescribed to people with ID who exhibit aggressive behaviour (Taylor et al, 2011; Unwin et al, 2011a; Deb et al, 2001a).

Concern has regularly been expressed over the use of psychotropic medication to manage aggressive behaviour in people with ID without a diagnosis of an underlying psychiatric illness (Hemmings et al, 2013; Edwards et al, 2007; Tyrer & Hill, 2000) and psychiatrists in the UK would prefer to implement non-medication-based interventions as first line (Unwin & Deb, 2008). It has been reported that 36% of adults with ID who do not have a diagnosis of psychiatric illness, receive psychotropic medication (Clarke et al, 1990). This has been termed ‘off-label’ prescribing, where a medication is used outside the terms of its Marketing Authorisation (Haw & Stubbs, 2005). To date there have been few reports about the use of off-label prescribing in psychiatry, however, off-label prescribing is considered common practice. A study of 100 adults with ID in receipt of psychiatric services for aggressive behaviour reported that over 90% were in receipt of psychotropic medications, although a proportion of these individuals may also have received psychiatric diagnoses (Unwin et al, 2011b).

Non-medication-based interventions such as psychotherapy, behavioural therapy, environmental manipulation and positive behavioural support have been used with some success. However, as with reviews of research into medication efficacy, reviews of non-medication based interventions have identified a lack of good quality evidence in the area, including small sample sizes, lack of comparative control groups, lack of intention to treat analyses used in randomised controlled trials, short follow-ups, limited outcome measures (often measuring only frequency of behaviour) and lack of stringent definitions of aggressive behaviour (Nicholl et al, 2013; Hassiotis & Hall, 2008; Carr et al, 1999). A Cochrane review of behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in children and adults located four RCTs all reporting positive results of intervention over control group (Hassiotis & Hall, 2009). Willner (2005) also found support for the effectiveness of cognitive-behavioural, cognitive and psychodynamic therapies for the management of problem behaviour in people with ID, whilst acknowledging that efficacy literature is limited and in particular, very few randomised controlled trials exist in the field. To address this, two recent RCTs have indicated that group cognitive behavioural therapy for management of anger in adults with ID and intervention from specialist behaviour support teams may be cost-effective options and have positive effects on challenging behaviour (Willner et al, 2013; Hassiotis et al, 2009). Furthermore, a systematic review and meta-analysis of cognitive behavioural therapy for anger reported promising results from 12 studies (Nicoll et al, 2013).

Previously, meta-analyses have provided support for the effectiveness of non-medication-based interventions. Corrigan (1991) examined the effects of social skills training and concluded it had a consistent effect, as it improved behaviours by teaching more appropriate behaviours; however the authors comment that the included studies were of moderate quality. Carr and colleagues (1999) investigated the effect of positive behavioural support and concluded that positive behaviour increased following the use of positive behavioural support. This effect however, varied widely from modest to substantial and the quality of the studies included in the review is subject to criticism.

As the literature suggests, the role of interventions on the management of behaviour problems in adults with ID is unclear. However, a recent meta-analysis including 30 studies published between 2000 and 2008 of any intervention found an overall combined effect size of .67 (95% CI .57-.77, Heyvaert et al, 2010). No differences were observed in the effect size according to type of intervention (biological, psychotherapeutic, contextual, or sensory) or demographic profile (gender, level of ID, age etc.). This study indicates an overall positive effect of interventions; again however, poor methodological quality of the included studies compromises the results of the meta-analysis. Further research is needed to clarify the effectiveness of such interventions and to examine the appropriateness of particular interventions for certain individuals and topographies of aggression. Furthermore, given the perceived chronicity of aggressive behaviour and the effects on carers, as well as the impact carers can have on behaviours, future interventions may target carers specifically.

APPENDIX 2: PARTICIPANT INFORMATION SHEET

UNIVERSITY OF BIRMINGHAM

Information about the research

Information sheet for participants

Title of research: Effectiveness of interventions on aggression

You may like to get someone to help you go through this leaflet.

Introduction

Research is a way we try to find out the answers to questions.

We want to find out which treatments work best.

A treatment is a way of helping a problem. For example, a treatment might be

- different types of medicine you can take
- talking about what makes you angry, sad, upset or scared
- talking about how you behave
- talking about why you behave that way.

We are asking if you would take part in a research project to find out what treatments work best on aggression.

Aggression is things like

- hitting other people
- hurting yourself
- being angry
- screaming
- breaking things.

Before you decide if you want to join in it's important to understand why the research is being done and what it will involve for you.

Please consider this leaflet carefully.

Talk about it with your family, friends, doctor or nurse if you want to.

Please ask if you want to know more.

Please ask if you do not understand something.

Please take time to decide whether or not you want to take part.

Why are we doing this research?

People sometimes have problems with behaviour. Aggression is a behaviour problem which can cause problems for the person and their carers.

There are lots of ways to help aggression. However, we do not know which is the best.

We want to find out which treatments are best.
We will look at all treatments that are used, including

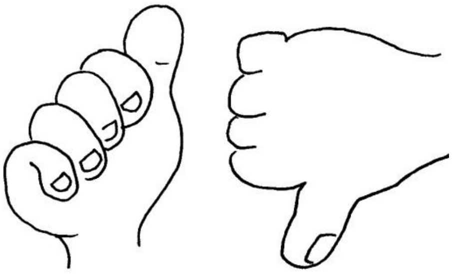
- medicines
- speech therapy
- talking therapies
- changing the environment
- daily activities.

Why have I been invited to take part?

You have been invited to take part because

- you have a learning disability
- you sometimes show aggressive behaviour
- you are aged 18 years or over.

We would like carers of 80 to 100 people with learning disabilities to take part in this research.



Do I have to take part?

No. It is up to you. You can decide whether or not you want to take part.

If you do want to take part, we will ask you to sign a form giving your consent or agreement.
You will be given a copy of this information sheet and your signed form to keep.

You can stop taking part at any time during the research without giving a reason.

If you decide to stop, this will not affect the care you receive.

What will happen to me if I take part?

We would like to ask your carer some questions about you, your behaviour and your health.

We will interview your carer 3 times over a period of 1 year.

Each interview will last about 1 hour and 30 minutes. You do not have to go to the interview.

We would also like to look at your health records. Your doctor has these. We want to find out what treatments you have had.

What will I be asked to do?

You will not have to do anything

during the study. Your carer will answer the questions.

Any health care or treatments you receive will carry on as normal.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help treat people with behaviour problems in the future.

Contact details

If you would like more information, please contact

Gemma Unwin
Telephone: [details removed]
Email: [details removed]
Address:
University of Birmingham
Department of Psychiatry
Edgbaston
Birmingham
B15 2TT

Thank you for reading so far.
If you are still interested, please go to Part 2.

Part 2

This part of the leaflet has more information about the research.

You will need to know this information to decide whether you want to take part.

What happens when the research project stops?

When the research project is finished, you will carry on with any treatment you have received.

Any medical care or therapy you normally have will continue.

Your health care will not be affected in any way.

Might anything about the research upset me?

The research should not upset or distress you in anyway.

If the research does upset you, you should tell someone. You can make a complaint if you are not happy about the research.

You can make a complaint to [named removed] at the University of Birmingham. [Name removed] is not involved with the research.

His contact details are:
[Name removed]
University of Birmingham,
Edgbaston,
Birmingham,
B15 2TT.
Telephone: [details removed]
Email: [details removed]

What if I don’t want to take part in the research anymore?

If at any time you don’t want to take part in the research anymore, just tell the researcher, your carer, parents, doctor or nurse.

Will my medical details be kept private if I take part? Will anyone else know I'm taking part in this?

We will keep your information in confidence. This means we will only tell those who have a need or right to know.

We will only look into information after removing your name and address.

Who has reviewed the study? Did anyone else check the study is OK to do?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by a Research Ethics Committee.

Thank you for reading this.

Please ask any questions if you need to.

The pictures are from the CHANGE Health Picture Bank, CHANGE, Units 19/20, Unity Business Centre, 26 Roundhay Road, Leeds, LS7 1AB.

APPENDIX 3: CARER INFORMATION SHEET

UNIVERSITY OF BIRMINGHAM

Information about the research

Information sheet for carers

Title of Project: Effectiveness of interventions on aggression

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully. Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study.

Please ask if there is anything that is not clear or if you would like more information.

Take time to decide whether or not you wish to take part.

Part 1 of the information sheet

What is the purpose of the study?

This study aims to investigate how effective interventions are at managing aggression in adults with learning disabilities. People with learning disabilities tend to show more behaviour problems, such as aggression, than the general population. Aggression refers to things like physical aggression, verbal aggression, property destruction, self-injury, tantrums and screaming. There are many different interventions that can be used to help manage or treat aggression such as taking medication, anger management training, making changes in the environment, speech therapy, increasing daily activities and counselling. However, we do not know which interventions work best and in what circumstances. This study wants to see which interventions are most effective in different circumstances by taking a naturalistic observational stance. This means that we want to observe the effects of interventions that are implemented through natural practice rather than impose any interventions ourselves. By doing this, we can find out what works best in ‘the real world’.

Another aim of the study is to look at the life course of aggression in adults with learning disabilities. We therefore want to look back at how the aggression has presented itself over time. This includes investigating when the aggression first became a problem, how much contact with services the person has received and any previous interventions that have been used to manage the aggression. This is a new approach to the study of behaviour problems in adults with learning disabilities and has not been done before.

Why have I been invited?

You have been invited to take part because you care for an adult with learning disabilities who displays aggressive behaviour. We aim to recruit carers of 80-100 adults with learning disabilities.

Do I have to take part?

It is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care the person you care for receives.

What will happen to me if I take part?

We would like to interview you 3 times over the course of a year. One interview will take place upon recruitment to the study, one at 6 months after recruitment and one at 12 months after recruitment. Each interview will last approximately 90 minutes and we can have breaks if preferred.

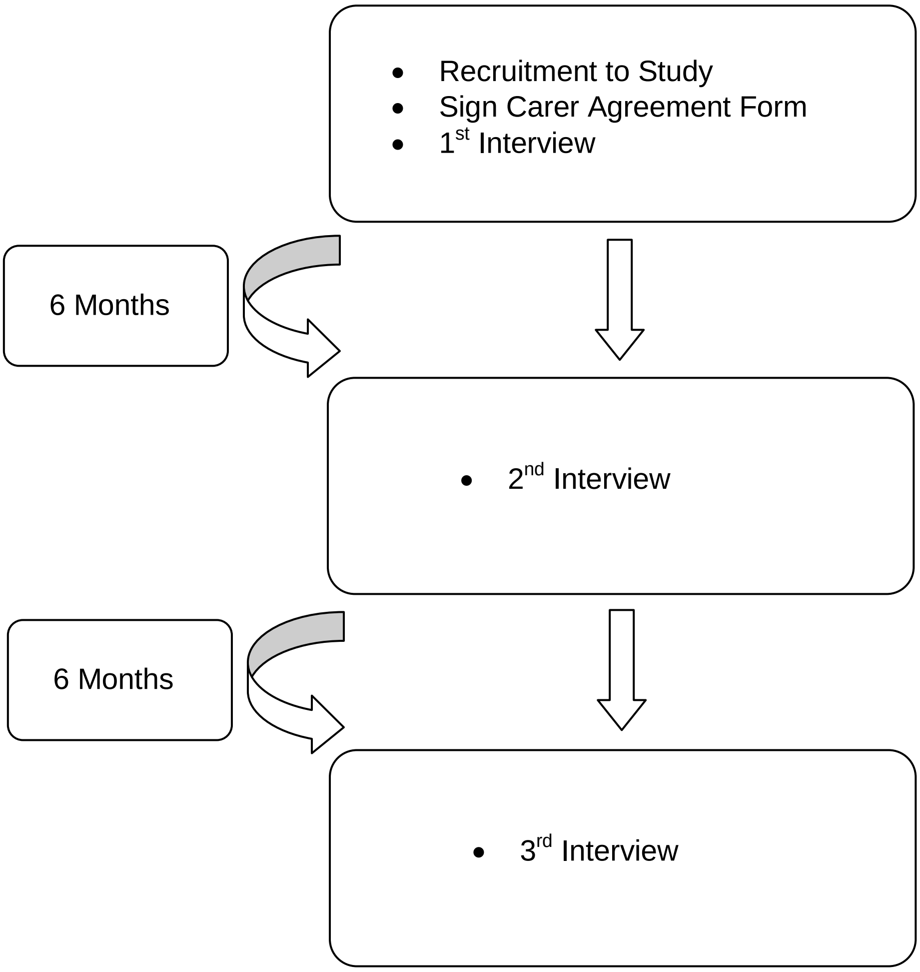
The interviews will take place at a mutually convenient venue. This could be your home, place of work, or the home of the person you care for. Therefore, you should not have to make a special journey to attend the interview.

All the interviews will be conducted by Gemma Unwin from the University of Birmingham who is the Chief Investigator and Researcher for the study. Before the first interview, Gemma will take you through this information sheet and answer any questions you have. If you want to take part in the study, you will then be asked to sign the Carer’s Agreement Form. This form is to gain your agreement for you and the person you care for to take part in the study. You will be given a copy of this information sheet for you to keep as well as a signed copy of the carer agreement form.

Once you have agreed to take part, Gemma will hold the first interview. Gemma will ask a series of questions in order to complete a number of questionnaires. Most of these questionnaires are standardised, validated, widely used questionnaires in this field of research. The questionnaires contain questions about the person you care for in relation to behaviour, mental health, physical health, quality of life and social issues. We will also ask some questions about how you feel about your caring role, this will only apply to family carers.

The study will not affect the healthcare received by the person you care for. We will not withhold any treatment, nor will any treatment be started because of your participation in the study. Any healthcare the person you care for received prior to starting the study will carry on as normal. However, the interviews conducted as part of this study are not part of routine healthcare. The interviews are in addition to standard diagnosis, treatment or management.

The following flow chart shows how the study will proceed:



What will I have to do?

We require participants to attend 3 interviews over 12 months. One interview will be held when you are recruited to the study, one at 6 months after recruitment and one at 12 months after recruitment. During this interview you will be asked questions about the person you care for. Your answers to the questions will be used to complete a number of questionnaires.

We also want to look at the healthcare records of the person you care for. If the person you care for has relevant healthcare records held with a specialist learning disability psychiatric service, we will want to review the records to find out what interventions have been implemented and when. We will use the healthcare records to find out more about the life course of the aggression. You will not have to do anything about this. We will complete the review ourselves.

What are the possible disadvantages and risks of taking part?

During the interviews we will be asking you about the aggressive behaviour the person you care for displays. This might be upsetting for you. If, at any time, you become upset during the interviews, we will stop the interview. You can ask for the interview to be stopped at any time.

What are the possible benefits of taking part?

We cannot promise the study will help you or the person you care for directly, but the information we get from this study should help improve the treatment of people with learning disabilities who display aggressive behaviour.

What happens when the research study stops?

After the third interview, involvement with the study from you will finish. We will have all the information we need by this point. Any healthcare the person you are caring for has been receiving will continue as normal. We will contact you after all the data have been collected and analysed to invite you to receive a summary of the results. This summary will be of the overall results and not specific about the information you provided.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you and the person you care for will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the Information Sheet

What will happen if I don’t want to carry on with the study?

If you decide you do not want to carry on with the study, we will not ask you to take part in any future interviews. Any information you have provided will not be used in any publications. If you wish, we will destroy any information you have provided.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions.

Researcher’s contact details:
Gemma Unwin
Telephone: [details removed]
Email: [details removed]
Address: University of Birmingham, Department of Psychiatry,
Edgbaston,
Birmingham,
B15 2TT.

If you would like to make a complaint about this study, you can make a complaint to the Sponsor.

Contact Details for the Sponsor:
[Name removed]
University of Birmingham
Telephone: [details removed]
Email: [details removed]
Address: University of Birmingham,
Research and Commercial Services,
Edgbaston,
Birmingham,
B15 2TT.

If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital, from your community nurse, from your doctor, or from the NHS website.

Harm

Any negligent harm arising from the management of the research is covered by the study sponsor’s insurance and indemnity arrangements. The sponsor of the study is the University of Birmingham. Claims for negligent harm may therefore be made to the study sponsor via their Public Liability Policy. There is no cover available for non-negligent harm arising from the design of the research. Therefore, no provision has been made for indemnity in the event of a claim for non-negligent harm.

Will my taking part in this study be kept confidential?

Yes. All information that is collected about you or the person you care for during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital/surgery will have your name and address removed so that you cannot be recognised. Similarly, with the name and address of the person you care for. Instead of using you name and the name of the person you care for, we will assign you an identification number. This identification number will be used on all information that you provide, including the questionnaires that are completed through interview. All the data collected will be hand written on the printed questionnaires.

For the purposes of contacting you, we will need to keep a record of your name, address and contact details. We will also need to keep this information for the person you care for. This information will be kept in a secure, locked cabinet, separate from the completed questionnaires, held in the main research site.

Only authorised persons will view any identifiable data. The Chief Investigator will have access to the identifiable data. In addition, it may be necessary for regulatory authorities or NHS Research and Development Agencies to view some of the data. However, this will be done on a strict ‘need to know basis’. Therefore, only those individuals who need to access person-identifiable information will have access to it, and they will only have access to the information items that they need to see.

Other people involved in the study may also view the data collected, however, this data will be anonymised. These people might be the Chief Investigator’s Educational Supervisor, a Statistician or auditors on behalf of the Sponsor.

We will keep personal information for a maximum of six years. All personal data will then be disposed of securely and shredded. Gemma Unwin, as Chief Investigator for the project will act as custodian for the data. All the data collection, storage and processing will comply with the Data Protection Act, the University of Birmingham Code of Conduct for Research and NHS Research Governance Framework.

Involvement of the Consultant Psychiatrist

If the person you care for is in contact with a psychiatrist for their aggression, we will inform the psychiatrist about your participation in the study in order to seek consent to have access to health records.

What will happen to the results of the research study?

The results of the study will be disseminated in several ways. You or the person you care for will not be identified in any report or publication unless you have given your consent. The results will be published in peer reviewed scientific journals in the form of research papers. The results will also be summarised and reported back to the funding body. A doctoral thesis by the Chief Investigator will also be published and made available in the University of Birmingham Library. Furthermore, conference presentations may be made to further publicise the results of the study.

Participants and their carers will also be invited to receive a summary of the results. Those who express interest in receiving the results will be sent a brief summary of the main research results. This will not be person-specific but will be general.

Who is organising and funding the research?

The research is being funded by the Baily Thomas Charitable Fund. The University of Birmingham is organising the research.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well being and dignity. This study has been reviewed and given a favourable opinion by a Research Ethics Committee.

A steering group will monitor the progress of the study. Members of this group include people from a wide range of relevant backgrounds including carers, psychiatrists specialising in learning disabilities, psychologists and nurses. Furthermore, people with learning disabilities will also provide advice from outside the group.

Further information and contact details

If you would like further information on this research, please contact:

Gemma Unwin
Telephone: [details removed]
Email: [details removed]
Address: University of Birmingham, Department of Psychiatry,
Edgbaston,
Birmingham,
B15 2TT

If you would like to know more about medical research in general, you can go to the National Patient Safety Agency website and look at information provided by the National Research Ethics Service.

You might like to talk to your doctor or the doctor of the person you care for, or another health professional about the study. You can also get more information about public participation in the NHS and research from Involve. Their website is www.involve.org.uk, and their telephone number is [details removed]. You can get more information about caring from the government from www.carers.gov.uk. You can get help and support from the Princess Royal Trust for Carers. Their website is www.carers.org and their telephone number is [detail removed] (London Office).

Thank you for reading this, please ask any questions.

APPENDIX 4: CONSULTEE INFORMATION SHEET

UNIVERSITY OF BIRMINGHAM

Information about the role of Consultee

Information sheet for Consultees

Title of Project: Effectiveness of interventions on aggression

As a consultee, you should act on behalf of and in the best interests of the individual who cannot consent for themselves. Your role is to advise the researcher about the individual's wishes and feelings in relation to the project and whether they should join the research.

You should only agree for the individual to be included in this research project if you believe they would be willing to do so if they had capacity.

If the person shows any signs of resistance or indicates in any way that he or she does not wish to take part, you should not give your agreement for them to take part.

If you do not feel able to take on the role of consultee, you can suggest someone else to take on this role or ask that a nominated consultee be appointed to act on behalf of the individual.

APPENDIX 5: PARTICIPANT CONSENT FORM

UNIVERSITY OF BIRMINGHAM

Consent form for study

Your Name…………………………………………………….

The title of this study is the effectiveness of interventions on aggression.

This means I want to see how well different treatments work on helping aggression.

The name of the person who will be doing this study is Gemma Unwin.

Please go through this form carefully.

You may like to ask someone to help you go through this form.

If you do not understand anything, please ask.

If you would like to know more, please ask.

Agreement to take part in the study

I have read the information sheet or had it read to me.

I have been able to ask questions.

All my questions have been answered.

I have had the chance to talk to my friends, family and carers.

I know what this study is about.

I know how I will take part in the study.

I know that any information about me will be kept secret.

I know that no one will be able to identify me in any information that is presented.

I agree that the study results about me can be published but only if my identity is kept secret.

I know that I do not have to take part in this study.

I know that I can stop taking part in this study whenever I want to.

If I leave this study, I know that my doctors will still give me the best treatment.

I understand what this form tells me ☐

I agree to take part in this study ☐

Signed ……………………………………………………………

Date ……………………………………………………………..…

I have witnessed ………………………………………………..

giving consent to take part in the study.

Relationship with the person ……………………………………….

Signed ……………………………………………………………..

Date …………………………………………………………

I …………………………………………… (person taking consent) have told this person about the study.

I have given them the information sheet.

I have answered their questions.

To the best of my belief, they have understood what I have told them and they are giving free and informed consent.

Signed …………………………………………………………

Date ……………………………………………………….…

Participant Identification Number ……………………………

Centre …………………………………………………………..

One copy to be kept by the participant and one to be kept in the researcher site file.

The pictures on this sheet are from the CHANGE Health Picture Bank, CHANGE, Units 19/20, Unity Business Centre, 26Roundhay Road, Leeds, LS7 1AB.

APPENDIX 6: CARER AGREEMENT FORM

UNIVERSITY OF
BIRMINGHAM

Carer Agreement Form

Agreement to take part in study

Participant ID number.......................……………….

Carer's Name ....…………

Please read this form carefully. Please ask if you do not understand or would like more information.

Title of Study: Effectiveness of Interventions on Aggression

Name of Researcher: Gemma L. Unwin

	Please initial to confirm
• I have read the information sheet dated 10/12/07 (version 2) for the above study. I have had the opportunity to consider the information and ask questions about the study. All my questions have been answered satisfactorily.	[ ]
• I understand the purpose of the study, and how I will be involved.	[ ]
• I understand that I do not have to take part in this study. I understand that I do not have to allow the person I care for to take part in this study.	[ ]
• I understand that I, and the person I care for, can leave (withdraw from) this study at any time, without giving any reason.	[ ]
• I understand that all the information collected in the study will be kept strictly private and confidential. I understand that if information is presented or published, all personal details about me and the person I care for will be removed. I understand that our identities will be kept secret.	[ ]
• I understand that relevant sections of medical notes and data collected during the study may be looked at by individuals from the University of	[ ]

Birmingham, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I agree for these individuals to have access to these records.

- I confirm that I will be taking part in this study of my own free will, and I understand that I may withdraw from it, at any time and for any reason, which will not affect the medical care or legal rights of the person I care for. **[ ]**

I agree to take part in this study and I agree for the person I care for to take part in this study.

Name: ………………………………………

Signed: …………………………………….. Date: ……………………

I, …………………………………………(person taking consent) confirm that I have told the above about this research project. I have given them the carer information leaflet, and have answered any questions they have asked. To the best of my belief, s/he has understood what I have told her/him and s/he is giving free and informed agreement.

Signed: …………………………………….. Date: ……………………

When completed, one copy to be kept by the carer and one to be kept researcher site file.

APPENDIX 7: BACKGROUND/REGISTRATION QUESTIONNAIRE

Participant’s Name: ………

Identification Number: ………………………………………………………………………………………………………

Participant’s Address: ………………………………………………………………………………………………………

……

……

Participant’s Date of Birth: …………………………………………………………………………………………………

Name of Community Learning Disability Team: ………………………………………………………………………

Carer’s Name: ………

Identification Number: ……………………………………………………………………………………………………

Carer’s Address (if different from above): ………………………………………………………………………

……

……

Carer’s Date of Birth: ……………………………………………………………………………………………………

Once completed, remove sheet from rest of questionnaire and store securely.

BACKGROUND/REGISTRATION QUESTIONNAIRE (CONTINUED)

Identification Number: ……………………………….

Date: ………………………………………………….........

1) Status of carer answering the questions (tick applicable box):
    - Care worker (paid carer) ☐
    - Parent of participant (family carer) ☐
    - Sibling of participant (family carer) ☐
    - Other family carer ☐
        - Please specify……….……………………..
    - Volunteer Carer (unpaid, non-family member) ☐
    - Other ☐
    - Please specify ……………………………….........

2) Length of time carer has known the participant (specify number of years):

    ………………..years
    - Since birth ☐
    - Don't know ☐

3) Participant's Gender (tick applicable box):
    - Male ☐
    - Female ☐

4) Participant's marital status (tick applicable box):
    - Single/never married ☐
    - Married/living with partner ☐
    - Separated/divorced ☐
    - Widow/widower ☐
    - Other ☐
        - Please specify…………………….............
    - Don't know ☐

5) Participant's level of ability (learning disability) (tick applicable box):
    - Borderline ☐
    - Mild ☐
    - Moderate ☐
    - Severe ☐
    - Profound ☐
    - Don't know ☐

6) Participant's IQ level:

    ……………………….
    - Don't know ☐

7) Participant's ethnic group (tick applicable box):
    - White (English Scottish or Welsh) ☐

White Irish [ ]
Other White [ ]
Please specify……………………………..
Black African [ ]
Black Caribbean [ ]
Other Black [ ]
Please specify……………………………..
Indian [ ]
Pakistani [ ]
Bangladeshi [ ]
Chinese [ ]
Other [ ]
Please specify……………………………..
Don’t know/not sure [ ]

8) Participant’s current living situation (tick applicable box):
Domestic/Family [ ]
Owner occupied flat or house [ ]
Privately rented flat or house [ ]
Rented from local authority/housing association [ ]
Community Home (Non-hospital) [ ]
Overnight facility, 24 hour, staffed [ ]
Overnight facility, staffed, not 24 hour [ ]
Overnight facility, unstaffed at all times [ ]
Hospital [ ]
Long-stay psychiatric ward [ ]
Rehabilitation psychiatric ward [ ]
Assessment ward [ ]
General medical ward [ ]
Homeless/roofless [ ]
Other [ ]
Please specify ……………………………………..

9) Level of education the participant has received (tick applicable box(es)):
No education [ ]
Primary education or less [ ]
Secondary education [ ]
Special education [ ]
Community college [ ]
Tertiary/further education [ ]
Other [ ]
Please specify……………………………..
Don’t know [ ]

How many years schooling did the participant receive? ……………………

10) Cause of the participant’s learning disability (tick applicable box):
Genetic Syndrome (for example Lesch-Nyhan, Prader-Willi, Down Syndrome or Fragile-X Syndrome) [ ]
Please Specify ………………………………………………
Abnormal birth (peri-natal brain injury) [ ]
Other [ ]

Please specify……………………………………….
Unknown origin [ ]
Don’t know [ ]

11) At what level does the participant communicate verbally? (tick applicable box):
No language [ ]
Words and phrases [ ]
Full sentences [ ]
Don’t know [ ]

12) Does the participant have any mental health problems? (tick applicable box):
Yes [ ]
Please specify…………………………………......
No [ ]
Don’t know [ ]

13) Does the participant have any behavioural problems other than aggression? (tick applicable box):
Yes [ ]
Please specify…………………………………......
No [ ]
Don’t know [ ]

14) Does the participant have any physical illnesses? (tick all that apply):
Yes, Epilepsy [ ]
Yes, Other [ ]
Please specify…………………………………......
No [ ]
Don’t know [ ]

15) Does the participant have any other medical conditions? (tick all that apply):
Obesity [ ]
Underweight/ malnutrition [ ]
Hypertension/ raised blood pressure [ ]
Urinary tract infection [ ]
Asthma [ ]
Impacted ear wax [ ]
Dental conditions [ ]
Dysphagia [ ]
Dry skin [ ]
Fungal infections [ ]
Eczema [ ]
Other [ ]
Please specify…………………………………………..

16) Does the participant have any impairment? (tick all that apply)
Yes, sensory impairment [ ]
Please specify ……………………………………….
Yes, physical disability [ ]
Please specify…………………………….
No [ ]
Don’t know [ ]

17) Is the participant receiving any current treatment for their aggression? (tick all that apply):

Yes, medical treatment [ ]
  Please specify…………………………………........
Yes, medication [ ]
  Drug(s) and daily dose………………………........
Yes, non-medical treatment [ ]
  Please specify…………………………………........
No [ ]
Don't know [ ]

18) At what age did the participant first start showing aggressive behaviour? (specify age):

Age…………………………………
Before started caring for them [ ]
Don't know [ ]

19) At what age was medical help first sought for the aggression? (specify age):

Age………………………………………………………..
Already in contact with services when first started caring [ ]
Don't know [ ]

20) Do you know of any triggers for the aggression or what the motivation is for the aggression? (Give details):

………

………..

………..

21) Has there been any changes or life events that you think have affected the person's behaviour in the last six months, that were not part of an intervention for the aggression? (E.g. pre menstrual tension, jet-lag, weather, physical illness):

Yes [ ]
  Please Specify:
  Physical illness [ ]
  Fatigue [ ]
  Being bullied [ ]
  Major/frequent changes in staff at home or day service [ ]
  Major/frequent changes of peers/fellow residents [ ]
  Being a victim of theft of other crime [ ]
  Break-up of important friendship [ ]
  Illness of relative/friend/favourite staff member [ ]
  Bereavement [ ]
  Moving house [ ]
  Accident [ ]
  Other……………………………………………………. [ ]
No [ ]
Don't know [ ]

APPENDIX 8: MODIFIED OVERT AGGRESSION SCALE (MOAS)

[Omitted from electronic copy due to copyright]

APPENDIX 9: ABERRANT BEHAVIOUR CHECKLIST (ABC)-COMMUNITY

[Omitted from electronic copy due to copyright]

APPENDIX 10: CARER’S UPLIFT AND BURDEN SCALE

[Omitted from electronic copy due to copyright]

APPENDIX 11: MINI PSYCHIATRIC ASSESSMENT SCALE FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

[Omitted from electronic copy due to copyright]

APPENDIX 12: CARER'S CONCERNS QUALITY OF LIFE QUESTIONNAIRE

Identification Number: ……………………………….

Date: ……………………………………………………........

Assessment: Initial/baseline [ ]
Follow-up 1 (6 months) [ ]
Follow-up 2 (12 months) [ ]

Carer's Concern
Are you concerned about (name of the person you are caring for)?

	Not Concerned	Mildly Concerned	Moderately Concerned	Very Concerned	Seriously Concerned
His/her physical health					
His/her mental health					
His/her self esteem					
His/her aggression					
Missing work/school/day care					
Risk of accident					
His/her future					
Lack of services					

Quality of Life
How would you qualify (name of the person you are caring for)?

	Very good	Good	Satisfactory	Poor	Very Poor
Relationships with others (within home)					
Relationships with others (outside home)					
Leisure and recreation opportunities					
Communication skills (within home)					
Communication skills (outside home)					
Self care skills					
Mobility					
Access to community facilities					

(**REFERENCE**: Deb & Unwin, 2007)

APPENDIX 13: FOLLOW-UP QUESTIONNAIRE

Identification Number: ……………………………….

Date: …………………………………………………….........

Assessment: Follow-up 1 (6 months) [ ]
Follow-up 2 (12 months) [ ]

1) Has the person been better/worse/no change?
    - Better [ ]
    - Worse [ ]
    - No change [ ]
    - Don’t know/not sure [ ]

Comments………

………

2) What do you think has had a positive/negative impact on the aggression (including any interventions that have been implemented)?

Comments………

………

3) Has there been any changes or life events that you think have affected the person’s behaviour since the last meeting, that were not part of an intervention for the aggression? (E.g. pre menstrual tension, jet-lag, weather, physical illness):
    - Yes, please specify [ ]
        - Physical illness [ ]
        - Fatigue [ ]
        - Being bullied [ ]
        - Major/frequent changes in staff at home or day service [ ]
        - Major/frequent changes of peers/fellow residents [ ]
        - Being a victim of theft of other crime [ ]
        - Break-up of important friendship [ ]
        - Illness of relative/friend/favourite staff member [ ]
        - Bereavement [ ]
        - Moving house [ ]
        - Accident [ ]
        - Other……………………………………………………. [ ]
    - No [ ]
    - Don’t know [ ]

4) How has the aggression manifested itself over the last six months?

Comments………

………

5) What are the current triggers or motivations for the aggression?

Comments………

………..

APPENDIX 14: ASSESSMENT OF CAPACITY TEST

Identification Number: ……………………………….

Date: ………………………………………………….........

What is the specific decision/action needed to be taken, for which the individual requires capacity?

To decide whether or not to take part in the research project.

Have you made every effort to assist the individual to make this decision themselves?

Yes / No

The Test

Can the individual understand the information necessary to make this decision at this time?

Yes / No

Can the individual retain the information for long enough to make this decision?

Yes / No

Can the individual weigh up the information in order to make the decision?

Yes / No

Can the individual communicate their decision?

Yes / No

If the answer to any question in this test is 'No', the individual does not have capacity to make this decision at this time. If all four are 'yes', the individual should make the decision.

Result: The individual has Capacity for this specific decision Yes / No

Comments/ Observations:

……

……

……

APPENDIX 15: CARER'S CONCERNS/QUALITY OF LIFE QUESTIONNAIRE DEVELOPMENT AND EVALUATION OF PSYCHOMETRIC PROPERTIES

Introduction

Quality of life is a multidimensional construct recognised as an essential component in outcome measurement (Townsend-White et al, 2012). As Verdugo and colleagues (2005) suggest, 'the importance of the valid assessment of quality of life (QOL) is heightened with the increased use of the of the QOL construct as a basis for policies and practices in the field of intellectual disability' (p. 707). Many quality of life scales for the general population are intended to be completed by the person themselves, to measure subjective quality of life. However, this poses a problem in ID research where informants are often used in data collection owing to communication and cognitive difficulties of the person. In clinical and research settings, sometimes the person may not be able to express how they feel and whether they feel any better and often such information is collected from a carer attending the appointment to support that person. Some quality of life scales indicate that they can be completed by the person or by an informant. However, it is questionable whether informants can reliably report on the subjective quality of life of someone else, for example, commenting on life satisfaction experienced. Therefore, informant-rated scales tend to use more objective indicators of quality of life. It is proposed however, that the assessment of quality of life should include both subjective and objective measures (Verdugo et al, 2005).

Quality of life scales designed for the general population often have objective items that may not be relevant to an individual with ID who, because of their impairments, might not be able to go out on their own, live on their own, manage their money or look after a family. As such, specific quality of life scales are required for people with ID, although a recent systematic review of quality of life measures for people with ID and challenging behaviours could not locate any instruments that assessed quality of life in this group (Townsend-White et al, 2012). The authors conclude that 'more instruments that measure [quality of life] need to be developed and rigorously validated' (p.270). In response, the following briefly reports on the development and evaluation of the Carer's Concerns/Quality of Life Questionnaire.

The Development of the Carer's Concerns/Quality of Life Questionnaire

The scale was originally developed by a Consultant Psychiatrist specialising in ID for use in his clinics (SD) with the intention of more objectively measuring quality of life of the patient and their carer and to track intervention effects. The scale was developed due to a lack of appropriate available scales that were quick and easy to use and had proven reliability and validity. The aim was to develop a brief, informant-rated, holistic measure to assess outcome in adults with ID who exhibit aggressive behaviour.

The scale comprises two parts to measure two constructs, namely outcomes for carers, in relation to concerns they have about the person they care for, as well as quality of life of the patient separately. Whilst it is acknowledged that there will be some overlap, as carer's level of concern may affect how they perceive the person's quality of life, it is argued that both are distinct and important to measure. It has been established that aggressive behaviours have a significant impact on carers (Unwin & Deb, 2011a), it is therefore important to consider the effects on carers as well as the person themselves when measuring outcome, including when evaluating interventions. An effective intervention may be one that does not have any overt impact on the behaviour but which supports carers, making them feel more able to cope, and more confident in supporting the person. This may then have a positive impact on both the carer's and person's quality of life as the carer might be more inclined to support the person in accessing more day activities or the placement security for the person may be improved by reducing the risk of placement breakdown. Furthermore, existing research recommends that outcome measurement for people with ID should include both the perspective of the person and family members and service providers (Townsend-White et al, 2012).

The items on each subscale were selected through clinical observation, expert opinion and through existing research on quality of life in people with ID. There is currently international consensus on the core domains of quality of life for people with ID (Verdugo et al, 2005; Schalock et al, 2002). Townsend-White and colleagues (2012) report eight core domains of quality of life that have been identified and extensively validated, namely, emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and rights. The items on the questionnaire were therefore selected to broadly cover these domains, whilst keeping the questionnaire short, quick to administer and unambiguous. Townsend-White and colleagues (2012) suggest that instrument brevity is an important feature. Some of these domains were operationalised through expert opinion to provide more objective questions that are relevant to people with ID. For example, access to community facilities broadly covers the concepts of self-determination, social inclusion and rights.

The questionnaire uses a five-point scale to assess each item. Commonly, five-point scales are advised in scale development literature (Clark-Carter, 2001) and as Lissitz & Green (1975) suggest, there is a levelling off in increased reliability after five scale points. In addition, Cummins (1997), in a review of quality of life measures for people with ID, suggests that five-point scales generally reflect about 95% of the underlying variation. Cummins also highlights that there is a trade off between increased reliability when there is a binary choice and issues of discrimination and validity, which require a larger number of choice points (see Chang, 1994 for a review of these issues).

The psychometric properties of the Carer’s Concerns/Quality of Life Questionnaire had not been established. Therefore, data were collected during the present study to allow for the assessment of various aspects of reliability and validity of the scale. It is important to investigate the measurement error in rating scales and questionnaires, as this can have an impact on statistical analyses and subsequent conclusions (Shrout & Fleiss, 1979).

Methods

The assessments of reliability and validity followed the methods outlined by Streiner and Norman (2003). Face validity of the scale was assessed during the pilot phase of the study. The interviewer (GU) made notes based on their impressions of the utility and feasibility of the scale. These issues were also discussed with carers, especially in light of difficulties experienced in using the Quality of Life Questionnaire (Schalock and Keith, 1993). Verbal feedback was obtained from carers on the questionnaire to assess how well it was received.

Data were collected at the time of the initial interviews (T1) to allow for test-retest and inter-rater reliability testing. Test-retest seeks to investigate the consistency of measurement over time, therefore, carers were asked to complete two copies of the questionnaire so that the correlation between their scores could be investigated. At the first interview, carers completed the Carer's Concerns/Quality of Life Questionnaire in the presence of the researcher and were then left a blank copy with a freepost envelope to be completed in a week's time and posted back. Blinding to previous response was ensured, as the completed copy of the questionnaire was kept by the researcher after the interview. A week time-lapse between assessments was chosen to minimise contamination so that the carer could not recall their scores from initial completion, whilst also minimising the chance of a significant event which would genuinely affect concern or quality of life, such as major illness or implementation of a successful intervention. A longer time lapse is often recommended, for example three months (Kline, 1999); however, these time scales are more appropriate for relatively stable, unchanging constructs such as intelligence quotient. Concerns and quality of life are likely to be rather transient and open to change, and therefore a shorter time frame was deemed more appropriate and the questionnaire was in fact designed to identify change of over time. The results of the two administrations were analysed using intra-class correlation coefficients (ICC). ICC reflects both degree of consistency and agreement among ratings in an attempt to overcome some of the short comings of correlation coefficients (Bruton et al, 2000).

Where available at T1, another carer was approached to complete an additional copy of the questionnaire, at the same time and in isolation from the original carer, to allow for the assessment of the consistency of the measure across raters (inter-rater reliability). Ideally, raters would have been chosen at random, however, they were sampled on an opportunity basis whereby another family or staff member of the household was asked to complete an additional copy of the questionnaire. Inter-rater reliability is particularly important in relation to the present questionnaire as carers are asked to rate the quality of life of the person they care for. Quality of life is a highly subjective construct, therefore, perceived quality of life could vary from rater to rater. For the questionnaire to be reliable, such rater effects would need to be minimal. Inter-rater reliability was analysed using ICC as it is commonly quoted as the preferred statistic for estimating inter-rater reliability (Streiner & Norman, 2003). ICC provides a reliability coefficient based on ‘the correlation between one measurement (either a single rating or a mean of several ratings) on a target and another measurement obtained on that target’ (Shrout and Fleiss, 1979, p. 422). In this way, ICC is suitable for estimating both inter-rater and test-retest reliability.

Cronbach’s alpha was used to model internal consistency of each subscale by averaging the correlation among items. Furthermore, a correlation matrix was computed to show the correlations between all items on each scale. These correlations indicate whether the scale is measuring a single dimension. Items that inter-relate well suggest that the items are related and are therefore measuring the same underlying dimension. Split-half reliability using Spearman-Brown correlation coefficient also assessed the homogeneity of each sub-scale (Steiner & Norman, 2003). Furthermore, the two-factor structure of the scale was assessed using bivariate Spearman’s correlation for the total subscale scores to investigate validity of the separation of the subscales of the questionnaire and the extent to which the total score for each subscale were related.

Criterion-related validity was measured by assessing concurrent validity (whether similar results achieved on the questionnaire correlated with results on other scales administered at T1). Ideally, concurrent validity would be assessed against a ‘gold standard’ in the field (Streiner & Norman, 2003). However, in the absence of such a gold standard, as described in the introduction, correlations with the other scales administered in the present study were used instead (weighted MOAS score, ABC-I score, family carer’s uplift score and family carer’s burden score). Whilst the other scales assessed different constructs, such as aggressive behaviour and carer’s outcomes, it can be asserted that the constructs of carer’s concerns and participant’s quality of life may be related to these, with increasing concerns being associated with increasing severity of aggression. Studies have demonstrated significant, positive, linear relationships between severity of aggression and family carer’s burden (e.g. Unwin & Deb, 2011) and severity of aggression and quality of life of the individual (Murphy, 2009; Myrbakk & von Tetzchner, 2008a). Contamination of scores was prevented by the carers being unaware that their scores on one scale would be assessed against their scores on another. Concurrent validity was assessed using Spearman’s correlation analyses.

All data were entered in to an IBM SPSS 19.0 spreadsheet to allow for analysis. Approximately half of the data were entered by an MRes Psychology student (MN) who was on a placement with the author.

Results

Data on the Carer’s Concerns/Quality of Life Questionnaire were available for 99 carers at T1. Table 1 provides a summary of the scores for each subscale and item on the questionnaire at T1.

Table 1: Descriptive statistics for scale and item scores on the questionnaire at T1 (N=99)

		Mean (SD)	Range
Carer's Concern	Total scale score	11.71 (7.12)	0-29
	Physical health	1.16 (1.17)	0-4
	Mental health	1.27 (1.25)	0-4
	Self-esteem	1.07 (1.16)	0-4
	Aggression	1.89 (1.20)	0-4
	Missing work/school/day care	0.69 (1.14)	0-4
	Risk of Accident	1.45 (1.24)	0-4
	Future	2.17 (1.44)	0-4
	Lack of Services	1.99 (1.56)	0-4
Quality of Life	Total scale score	19.67 (5.85)	6-31
	Relationships with others within the home	2.94 (1.00)	1-4
	Relationships with others outside the home	2.47 (1.21)	0-4
	Leisure and recreation opportunities	2.26 (1.15)	0-4
	Communication skills within the home	2.79 (1.01)	0-4
	Communication skills outside the home	2.06 (1.24)	0-4
	Self care skills	1.92 (1.18)	0-4
	Mobility	2.74 (1.01)	0-4
	Access to community facilities	2.48 (1.17)	0-4

Face Validity

Carers generally reported that the questionnaire was easy to understand and the items were relatively simple. They felt that each item was relevant and of importance to measure and that the scoring method was appropriate, provided enough options without being too detailed meaning that it was not difficult to select an option. The range in scores, either total or for each item, suggests that the items are sensitive and the measurement is appropriate as almost the full range of scores were obtained.

Test-retest (intra-rater) Reliability

Data on 52 test-retest sets were available. The mean time between each administration of the questionnaire was 8.65 days (SD: 3.08, range: 5-22 days). ICC was calculated for total subscale score and for each item. Table 2 provides a summary of the descriptive statistics for each item and the ICC based on the test-retest data. The ICC was based on a one-way random effects model where people effects were random, as in most cases each rater only rated one individual (Shrout & Fleiss, 1979).

Table 2: Summary of the scale and items scores for each rating at T1 (N=52)

		Rating 1	Rating 2	ICC (single measures)	95% CI
		Mean (SD)	Mean (SD)		
Carer's Concern	Total scale score	12.65 (6.96)	11.69 (6.47)	0.81	0.69-0.89
	Physical health	1.06 (0.94)	1.02 (0.98)	0.77	0.63-0.86
	Mental health	1.27 (1.24)	1.37 (1.05)	0.70	0.53-0.82
	Self esteem	1.29 (1.19)	1.21 (1.13)	0.71	0.55-0.83
	Aggression	1.85 (1.26)	1.67 (1.17)	0.62	0.42-0.76
	Missing work/school/day care	0.98 (1.31)	0.71 (1.05)	0.61	0.41-0.75
	Risk of accident	1.67 (1.29)	1.50 (1.23)	0.73	0.57-0.84
	Future	2.35 (1.30)	2.25 (1.28)	0.83	0.73-0.90
	Lack of services	2.19 (1.37)	2.19 (1.95)	0.46	0.21-0.65
Quality of Life	Total scale score	19.42 (6.19)	18.21 (6.14)	0.80	0.70-0.88
	Relationships with others within the home	2.94 (1.04)	2.67 (0.90)	0.66	0.47-0.79
	Relationships with others outside the home	2.44 (1.13)	2.38 (1.07)	0.77	0.63-0.86
	Leisure and recreation opportunities	2.13 (1.07)	2.15 (1.00)	0.67	0.48-0.79
	Communication skills within the home	2.79 (1.14)	2.62 (1.03)	0.65	0.47-0.78
	Communication skills outside the home	1.98 (1.29)	2.00 (1.21)	0.81	0.69-0.89
	Self-care skills	1.92 (1.22)	1.88 (1.17)	0.76	0.61-0.85
	Mobility	2.73 (0.99)	2.54 (1.08)	0.79	0.66-0.87
	Access to community facilities	2.48 (1.18)	2.12 (1.15)	0.67	0.49-0.80

The ICC for the carer's concern subscale score is 0.81 with a range of 0.46-0.83 across individual items. The ICC for the quality of life scale subscale score is 0.80 with a range of 0.65-0.81 across individual items. Carer's concern over the person's future was rated highest and also achieved the highest test-retest reliability. In terms of quality of life, the person's communication skills within the home achieved the highest test-retest reliability, followed by mobility. Chinn (1991) recommends that measures should have an ICC of at least 0.6 to be useful. Both scale scores and the scores for most of the individual items surpass this figure, it can therefore be asserted that the scale demonstrates good test-retest reliability, whilst only one item failed to reach this threshold (lack of services, ICC=0.46).

Inter-rater Reliability

Data were available for 50 sets of two raters. The relationships of the second carer included another family member or a care worker and they either worked or resided in the same household as the participant in the large majority of cases. Table 3 provides a summary of the descriptive statistics for each item and the ICC based on the inter-rater data. The ICC was based on a one-way random effects model where people effects were random, as in most cases each rater only rated one individual.

Table 3: Summary of the scale and items scores for each rater at T1 (N=50)

		Rater 1	Rater 2	ICC (single measures)	95% CI
		Mean (SD)	Mean (SD)		
Carer's Concern	Total scale score	12.02 (6.46)	12.88 (5.91)	0.67	0.50-0.80
	Physical health	1.26 (0.97)	1.26 (0.97)	0.31	0.04-0.54
	Mental health	1.26 (1.21)	1.68 (1.06)	0.51	0.28-0.70
	Self esteem	1.20 (1.13)	1.36 (1.31)	0.53	0.30-0.70
	Aggression	1.96 (1.28)	2.16 (1.18)	0.59	0.38-0.75
	Missing work/school/day care	0.82 (1.21)	0.78 (1.04)	0.51	0.27-0.69
	Risk of accident	1.52 (1.25)	1.58 (1.07)	0.49	0.25-0.67
	Future	2.14 (1.28)	2.08 (1.21)	0.63	0.43-0.77
	Lack of services	2.08 (1.40)	1.96 (1.20)	0.60	0.39-0.75
Quality of Life	Total scale score	19.58 (5.78)	18.30 (5.08)	0.63	0.43-0.77
	Relationships with others within the home	2.86 (1.03)	2.68 (0.98)	0.48	0.23-0.66
	Relationships with others outside the home	2.36 (1.17)	2.24 (1.02)	0.65	0.46-0.79
	Leisure and recreation opportunities	2.24 (1.12)	2.18 (1.04)	0.42	0.17-0.63
	Communication skills within the home	2.78 (1.04)	2.60 (0.95)	0.48	0.24-0.67
	Communication skills outside the home	2.06 (1.24)	2.20 (1.07)	0.60	0.39-0.75
	Self-care skills	1.88 (1.15)	1.64 (1.01)	0.65	0.45-0.78
	Mobility	2.84 (0.91)	2.50 (1.17)	0.51	0.27-0.69
	Access to community facilities	2.56 (1.15)	2.28 (1.07)	0.31	0.04-0.54

The ICC for the carer's concerns subscale is 0.67 with a range of 0.31 to 0.63 across the individual items. The ICC for the quality of life subscale is 0.63 with a range of 0.31 to 0.65 across the individual items. Carer's concern over physical health and quality of life, in terms of access to community facilities, showed the lowest inter-rater reliability. Carer's concern over the person's aggression and their future was scored most highly and these items also showed the highest inter-rater reliability. The items relating to quality of life in terms of relationships with others outside the home and self-care skills, achieved the highest inter-rater reliability in this subscale. As both subscale scores surpassed an ICC of 0.6, it can be asserted that both are reliable measures with consistency between raters.

Internal Consistency

Cronbach's alpha was 0.85 for carer's concern and 0.80 for quality of life. These correlation coefficients indicate good internal consistency for the scale, as an alpha coefficient of 0.7-0.8 is generally accepted as demonstrating acceptable reliability (Field, 2005), especially considering each scale only has eight items. As Streiner and Norman (2003) suggest, Cronbach's alpha is influenced by the number of items on a scale, with longer scales more likely to demonstrate homogeneity of items. Kline (1999) suggests that an alpha coefficient of 0.7 or lower can be acceptable for some psychological tests, due to the heterogeneity of some psychological constructs. Furthermore, Nunnally (1987, cited in Streiner & Norman, 2003) suggests that alpha should probably not be above 0.90, as this could indicate item redundancy.

An inspection of the Cronbach's alpha when each item was not included in the calculation indicates that all the items contribute towards this reliability. All items apart from one, namely the mobility item of the quality of life subscale, increased the alpha coefficient. Removal of the mobility item on the quality of life scale increased alpha to 0.81. However, this change is very small and therefore it does not warrant the mobility item being deleted from the scale (Field, 2005).

Analysis of the inter-item correlations for each subscale indicates that all items inter-relate reasonably well (r_s range: 0.22-0.64 for carer's concerns; -0.04-0.71 for quality of life) apart from the item mobility with relationships with others, both within and outside the home (0.09 and -0.04

respectively), and as discussed previously, this did not justify deletion of this item. None had a correlation coefficient over 0.8-0.9, which may suggest problems with multicollinearity or singularity (Field, 2005). Therefore, each item is related to each other item on each subscale, but each item remains distinct, measuring a different element of the construct. Similarly, the item-total correlations were inspected to ensure each item was adequately correlated with the subscale total score. A common cut-off for adequate item-total correlation is a coefficient of 0.3 (Field, 2005). All the items in the concern subscale correlated adequately with total score (r_s range: 0.53-0.66). The mobility item in the quality of life scale achieved a coefficient of 0.28, the other items were all adequately correlated (r_s range: 0.39-0.73). Again, as the item-total correlation is only just below the recommended cut-off, it is acceptable to retain this item in the scale.

Split Half Reliability

The Spearman-Brown correlation coefficients for carer's concerns and quality of life were 0.81 and 0.70 respectively.

Validity of the Two-Factor Structure

Bivariate correlations of the total subscale scores indicate that whilst the two subscale scores are related, they remain distinct. There was a significant correlation between the two subscale total scores ($p<0.01$), however the correlation coefficient of -0.39 indicates a moderate relationship.

Construct Validity - Concurrent Validity

Table 4 presents the results of the correlation analyses to investigate the relationships between carer's concern, quality of life and severity of aggression and family carer's outcomes. Carer's concerns was significantly related to severity of aggression and carer's outcomes ($p<0.05$). Quality of life was significantly related to both measures of severity of aggression ($p<0.05$), but was not related to outcomes for carers. The correlation coefficients indicate small to medium effect sizes.

Table 4: Correlation coefficients (rs) for concurrent validity

	Weighted MOAS	ABC-I	Carer’s Uplift	Carer’s Burden
Carer’s Concern	0.41**	0.46**	-0.30*	0.57**
Quality of Life	-0.22*	-0.21*	0.30	-0.26

*p≤0.05.
**p≤0.01.

Discussion and Conclusions

The reliability coefficients indicate that the Carer’s Concerns/Quality of Life Questionnaire is a reliable measure with good test-retest reliability, inter-rater reliability and internal consistency. Test-retest reliability was generally higher than inter-rater, which is perhaps anticipated as there is likely to be less inconsistency over time than between people. All measures of reliability were lower for the quality of life subscale than for the carer’s concerns subscale, perhaps reflecting the highly subjective nature of the construct being measured and the fact that carers were being asked to rate the quality of life of another individual, whilst they rated their own concerns in the carer’s concerns subscale. Inspection of the reliability of each individual item indicates that the majority of items demonstrate good reliability, apart from mobility in the quality of life subscale. Therefore, it is recommended that subscale scores are used rather than individual item scores.

The internal consistency analyses indicate that the items on each subscale are measuring the same underlying construct. Furthermore, the correlation between the two subscales indicate that they are significantly negatively correlated, however, the coefficient indicates a small to moderate effect, which justifies the two factor structure of the questionnaire. The subscales also relate to other measures of severity of aggression and outcomes for family carers as would be anticipated, indicating concurrent validity.

APPENDIX 16: NATIONAL RESEARCH ETHICS SERVICE LETTER OF FAVOURABLE ETHICAL OPINION

APPENDIX 17: DISCUSSION OF RECRUITMENT AND PARTICIPATION IN THE STUDY

Recruitment Rates

Participants were recruited from specialist community-based ID health services (CLDTs) in the West Midlands, United Kingdom. A total of 1,645 adults had attended one of the recruitment centres within 12 months of inspection of the case notes at that site. Eighty-eight per cent (n=1,449) of case notes were assessed against the inclusion criteria outlined in Chapter 2. It was not possible to inspect all the notes of patients attending each service, as their notes were in use elsewhere. Around 46% (n=662) of patients met the inclusion criteria, with aggressive behaviour being mentioned as a problem in the case notes within six months from the date of inspection (range: 26.19-100% across sites). This suggests that around 46% of patients attending CLDTs have some current issues with aggressive behaviour. One site was a specialist challenging behaviour service and hence, 100% of people attending that service were eligible to take part. The other nine services represented psychiatrist-led clinics.

A total of 662 letters of invitation were sent out with a response rate of almost 25%. This is lower than other studies using a letter of invitation recruitment procedure (for example, Manjer et al, 2002 reported a recruitment rate of 33% to a population-based cohort study of cancer using a letter of invitation and using interview-based data collection). Furthermore, not everyone who expressed an interest in taking part was actually recruited to the study. The proportions of people eligible to take part who were recruited ranged from 11-21% across sites with an overall percentage of 15.11%. However, it is known that it is more difficult to recruit and retain participants in the field of ID research than the general population (Oliver-Africano et al, 2010; Lennox et al, 2005). Lennox and colleagues (2005) report on these difficulties and, despite using innovative recruitment methods and extending their recruitment period, still only report a recruitment rate of around one third of potential participants.

Only around 61% of people who expressed an interest in taking part were actually recruited to the study. A record was kept of cases where a positive response to the letter of invitation was received but where the person was not included in the study (n=64). Table 1 provides a summary of the reasons for 'lack of conversion' into participation. Some of the reasons can be attributable to the fact that the present study used informants and collected data on people who might not be able to consent for themselves.

Table 1: Summary of common reasons for 'lack of conversion' from interest in study to participation

Reason for lack of conversion	Number (%)
Carer withdrew interest, repeatedly asked for more time to consider, or ceased to care for the person	21 (32.8)
Carer contacted several times and left messages, but could not be reached	20 (31.25)
No/incorrect telephone number supplied on the reply slip. Carer was sent a letter requesting a contact number but no response	7 (10.94)
The person was in contact with family but agreement from a relative could not be obtained	4 (6.25)
Carer initially interested in taking part but the person they cared for did not consent	3 (4.69)
Carer already taking part in interviews about other participants and could not commit any more time	3 (4.69)
An interview was arranged but had to be cancelled at short notice. It was no longer possible to arrange an interview	3 (4.69)
The person passed away before an interview could be arranged	1 (1.56)
The person was due to move house in the near future	1 (1.56)
The person was not in contact with family and the carer did not feel they could act as consultee	1 (1.56)
Total	64

The most common reason for lack of conversion was that the carer withdrew interest, continually asked for more time to consider or ceased to care for the person, either leaving their place of work or going on long-term sick leave. Some carers felt they were too busy to take part after reading the information sheet. The information pack sent out to carers contained three separate documents. It is suspected that some carers were overwhelmed at the length of the documents and did not have enough time to read them. As part of the consent process, it was essential that both carer and person with ID read their respective information sheet to ensure that they were fully informed and so carers were asked this question in follow-up phone calls. Some carers repeatedly asked for more time to read the information sheets. The fact that the information pack included three separate documents, one of which was very long due to its accessible format, probably served to amplify this issue. However, this was necessary for the study to conform to ethical standards, as discussed in Chapter 2.

It is well known that carers, either familial or paid, of adults with ID and aggressive behaviour are an under-resourced and under pressure group (e.g. Gray-Stanley & Muramatsu, 2011; Unwin & Deb, 2011a; Maes et al, 2003, see discussion in Chapter 1). This may account for the relatively low response rate and for carers withdrawing interest. Carers may have felt that they did not have enough time to participate, especially given the longitudinal nature of the study. Indeed, Lennox and colleagues (2005) reported early barriers to recruitment in their study being the ‘complexities and burdens of care’ faced by family carers (p. 298) and the ‘burn out and suspicion towards research’ felt by care workers (p. 299). In addition, Becker and colleagues (2004) highlight potential feelings of distrust towards research as a barrier to recruitment. They encountered some resistance from carers when they were contacted to arrange interviews with participants, even when the participant had already given consent.

As described in Chapter 2, the consent/agreement process for the present study was at times rather complex, requiring consultees to act in the best interests of anyone who lacked capacity to consent to take part in the study. Ideally, a family member would act as consultee, so in some cases a relative was contacted to seek their agreement. In four cases, it was not possible to obtain agreement from the relative, despite another carer initially being interested in taking part. In another case, the person was not in contact with family and the carer did not feel they wanted the responsibility of acting as consultee. Further reasons were related to the issue of requiring two or three parties to consent/agree: as the study utilised carers as informants, both carer and person cared for needed to agree to take part. Lennox and colleagues (2005) and Oliver-Africano and colleagues (2010) draw upon the complexity of the consent/agreement process as a potential barrier to recruitment and suggest that identifying third parties to act as consultee inevitably leads to necessary extensions of the recruitment phase.

Cleaver and colleagues (2010) also implicated the method of obtaining consent in affecting recruitment rates in their review of participation of adults with ID in research over a 20 year period from 1987 to 2006. Studies which sought agreement from a ‘substitute decision-maker’ only tended to have higher recruitment rates. However, these studies were conducted prior to the implementation of legislation regarding the acquisition of consent, and this would now be considered unethical for UK-based research. Issues around consent and agreement were evident in the present study, which sought to obtain consent directly from the participant in the first instance and then contact a consultee where the person lacked capacity. In three cases, the carer was initially interested in taking part but consent could not be obtained from the person with ID. Oliver-Africano and colleagues (2010) remark upon this potential difficulty in recruitment to their study; in some cases, adults with ID who lacked capacity but indicated that that did not want to participate were not included, despite agreement from a consultee.

Ability to contact the participant directly has also been identified as a salient factor affecting recruitment rates. Cleaver and colleagues (2010) reported that participation was higher when the researcher contacted the participant directly, rather than relying on a third party to introduce the study. This may have been an issue affecting recruitment rates in the present study as letters of invitation were sent directly to carers and not the participants. This method was chosen for practical issues, due to the reading ability of the potential participant not being known at the outset. Furthermore, as carers would be actively involved in the study, it was also appropriate to invite them to take part. Other studies have suggested that recruitment was best achieved through direct contact with a member of staff from a service provider, who could then pass on information to the person with ID and their family carers (Lennox et al, 2005). A further key reason for lack of conversion was the ability of the researcher to contact the carer. In all cases, several attempts were made to contact the carer but it proved impossible to make contact with some of them. Typically, there was no-one home to take the call, messages were left and not returned, or the paid care worker was not on shift at the time or out.

Nicholson and colleagues (2012) undertook a qualitative analysis of interviews with people who acted as intermediaries between people with ID (potential participants) and researchers, to understand more about the difficulties in recruiting people with ID to research projects in light of poor recruitment to their previous study. This study represents the first empirical research specifically designed to investigate the difficulties of recruitment in the field. They describe seven themes that were identified, including: participant factors, the research process, previous experience, active recruitment, and families and carers. Nicholson and colleagues (2012) report that all interviewees mentioned the complexity of the recruitment process as a potential barrier, and also problems around the complexity of the information packs handed out to potential participants. Furthermore, some families and carers were reported to be reluctant to participate in the research, even where the potential participant may have expressed an interest. The authors report that some people are simply not interested in partaking in research. Nicholson and colleagues (2012) go on to provide recommendations for future research to facilitate successful recruitment. However, the authors note that no family carers nor people with ID were included in the interviews and thus the barriers in recruiting people with ID via family intermediaries and the perspective of people with ID themselves has not yet been investigated.

Attrition

Table 2 provides a summary of the reasons for attrition. It is important to note that none of the participants or carers were asked to provide a reason for withdrawal; this is in line with research ethics guidance which states that participants do not need to give a reason should they want to withdraw from a study.

Table 2: Summary of reasons for loss to follow-up (N=39)

Reason for loss to follow-up	Number (% of those lost to follow-up)		
	Family carer	Paid carer	Total
Carer moved employment	0	7 (17.95)	7 (17.95)
Not able to arrange follow-up – not possible to find convenient time and date within two month window for follow-up	6 (15.38)	1 (2.57)	7 (17.95)
Participant moved residence	1 (2.57)	4 (10.26)	5 (12.82)
Not able to arrange follow-up – carer could not be contacted	4 (10.26)	1 (2.57)	5 (12.82)
Carer withdrew – carer did not want to be involved in follow-up	5 (12.82)	0	5 (12.82)
Carer withdrew – carer too busy at time of follow-up	3 (7.70)	2 (5.13)	5 (12.82)
Carer on long-term sick leave/carer unwell at time of follow-up	2 (5.13)	2 (5.13)	4 (10.26)
Carer passed away during follow-up	1 (2.57)	0	1 (2.57)

One of the most common reasons for attrition was that the carer moved employment. This is particularly pertinent in the field of ID research whereby informants, often carers, are used in data collection. As would be anticipated, all the withdrawals for this reason were where a paid carer had moved employment. It is known that there is a high staff turnover for paid care workers that work with people with ID, purported to be around 10-30% per year in the UK (Hatton et al, 1995; Felce et al, 1993). Another common reason for withdrawal is that the person themselves moved residence. Again, this is pertinent in longitudinal ID research, especially given the current trend in the care sector to move towards closing large residential units in favour of supported living. The majority of withdrawals for this reason came from those living in residential care homes. In two cases, the person’s home was closed and the person moved out into supported living. In another two cases, the person had to move to more secure accommodation due to their behaviours. This poses a particular problem, as those individuals would have been important to the follow-up and investigating the reasons for the deterioration in their behaviour, however it was impossible to obtain a forwarding address.

Further difficulties related to arranging the interview and finding a mutually convenient time and place. Effort was made to accommodate the needs of the carer and participant, as Lennox and colleagues (2005) suggest, ‘researchers must be prepared to make home visits and visits after hours to allow for time constraints of participants and carers’ (p. 304). However, in some cases it proved impossible to arrange an interview within the stipulated one month window either side of the interview due date. In most of these cases, interviews were initially scheduled but had to be cancelled at short notice for reasons such as bad weather, illness, or the carer had other appointments. This also relates to another reason for loss to follow-up in that the carer was too busy to take part in the interview; for some, the carer was too busy as a direct result of providing care to the participant. In an additional case where the carer withdrew, they did so as they felt it would be too difficult to accommodate the interview within the routines of their son who has ASD. Another carer withdrawal was also related to the nature of the topic of research: one parent carer withdrew as they felt that, owing to the escalation in their son’s behaviour, they would find it too traumatic to participate in the interview.

Many of the reasons for withdrawal are associated with the field and methodology of research, for example, a longitudinal study interviewing mothers of children with ID could only follow-up 63% of their original sample 18 months later (Lloyd & Hastings, 2008). Whilst the attrition rate may be higher than that anticipated by other studies, it is probably acceptable once the reasons are examined more closely.

APPENDIX 18: REPRESENTATIVENESS OF THE SAMPLE – COMPARISONS WITH LARGE-SCALE STUDIES

To report on the representativeness of the study sample with other populations of adults with ID, comparisons are made between the demographic profile of the sample with those reported in large-scale epidemiological studies. Initially, comparisons of demographic variables with the general ID population are made with a recent Department of Health report (DH, Emerson et al, 2011a). Comparisons are also made with a large sample of adults with ID who received psychiatric services (a clinic-based sample with various diagnoses) and a sample of adults with ID who showed aggressive behaviour and were in contact with services (Sigafoos et al, 1994).

Comparisons of the Study Sample to the General ID Population

A recent report published by the Department of Health sought to assimilate epidemiological information on people with ID in England from a range of sources (Emerson et al, 2011a). Table 1 provides a summary of demographic variables for the present study sample compared to population-based and administrative (those known to services) estimates from the recent DH report. Emerson and colleagues (2011a) estimate that in 2010, there were 900,000 adults with ID living in England. Of which, 58.44% were male and 41.56% female. This is comparable with the cohort proportion of 63% male. However, the proportion is higher than both population-based estimates and proportions based on those known to services. Given that some studies have found aggressive behaviour to be more prevalent in males, this is perhaps to be expected. The present cohort was also skewed towards younger adults when compared with population-based estimates of age. Again, this may reflect a trend towards aggression being more prevalent in younger adults than older adults (see Chapter 1 for a discussion of existing research).

Table 1: Sample characteristics and population-based characteristics

Characteristic		Sample %	Emerson et al (2011a)	
			Population %	Known to Services %
Gender	Male	63	58.44	56.36
	Female	37	41.56	43.64
Age group[a]	18-19	3.1	4.08	4.76
	20-29	31.6	20.41	21.23
	30-39	28.6	18.43	19.97
	40-49	17.3	19.96	23.29
	50-59	12.2	14.66	14.77
	60-69	5.1	11.70	10.15
	70-79	2.0	6.80	4.11
	80+	0	3.96	1.73
Place of residence	Registered/residential care/nursing home	53	-	20.27
	Family or friends	39	-	30.65
	Own home/supported living	7	-	27.60
	Other accommodation	1	-	21.48
Carer (family carers only, N=44)	Parent (own/adopted/step)	95.45	-	75.6
	Spouse/partner	0	-	6.9
	Other relative	4.54	-	10.9
	Child (caring for a parent)	0	-	4.7
	Other non-relative	0	-	1.5

[a] Data were not available for all participants

The report summarizes that, according to information collected on social care services utilised by adults with ID, 136,450 adults with ID were reported by local authorities to be in some form of accommodation, of which 83,245 were in settled accommodation. Of those who were in settled accommodation, 31% were reported to be living with family or friends. This rate is lower than the study cohort proportion of 39%. There are also differences in the proportion of people within registered care/nursing homes. This is probably due to differences in definitions and categories used in the report compared to the present categories, which makes a comparison difficult. In the present study, a much broader definition of 'community-based group home' was used to indicate that people were residing in a group home (two or more residents) and receiving 24 hour support. Therefore, this included registered care homes, NHS facilities, and some supported accommodation arrangements where there was more than one resident with 24 hour support.

The report also provides details on non-professional carers of adults with ID in England (Emerson et al, 2011a). The report provides statistics on the numbers of various non-paid carers, the majority of which are parent carers, as with the current sample. Only a minority are cared for by other family members or by non-relatives.

Comparisons of the Study Sample to a Population-based Sample of Adults Receiving Psychiatric Services

Bhaumik and colleagues (2008a) performed a cross-sectional survey of all adults with administratively defined ID in Leicestershire and Rutland, UK. The authors suggest that the area is similar in socio-economic terms to the UK as a whole; the area is also likely to be representative of the West Midlands region from which the present sample was drawn. The authors collected a range of demographic information on adults (aged 19 years or over, either inpatient or outpatient) who used specialist psychiatric services from the Learning Disability Service in Leicestershire over a six year period (n=1,244). Table 2 presents a comparison of the sample characteristics with those reported by Bhaumik and colleagues (2008a).

On inspection of the characteristics of each sample, it is evident that a greater proportion of males were included in the present sample compared to the prevalence of males in Bhaumik and colleagues' (2008a) population. Furthermore, the trend towards younger adults persists. Again, these differences may be accounted for by existing evidence, suggesting that aggressive behaviour is more common in males and decreases with age. Bhaumik and colleagues' (2008a) sample tended towards more severe ID, containing fewer participants with mild or moderate ID than the present sample, and this may be explained by the inclusion of inpatients in Bhaumik and colleagues' (2008a) study. Ethnicity is comparable, as is the rate of adults living in residential homes; however more people lived with family members in the study sample.

Table 2: Current sample characteristics compared with the characteristics of a large sample of adults on the Leicester Learning Disabilities Register

Characteristic		Sample N=100 %	Bhaumik et al (2008a) N=1,244 %
Gender	Male	63	56.8
	Female	37	43.2
Age group[a]	18-29	34.7	20.4
	30-39	28.6	23.8
	40-49	17.3	23.4
	50-59	12.2	19.1
	60+	7.1	13.3
Place of residence	Residential home/Social Services hostel/NHS accommodation	53	52
	Family home	39	27.4
	Own home/independent/ supported living	7	9.3
	Other/not known	1	7.1
Ethnicity	White	87	87
	Minority ethnic group	13	13
Level of ID	Mild	23	12.9
	Moderate	32	15.0
	Severe	41	33.3
	Profound	4	38.8

[a]Data were not available for all participants

Comparisons of Study Sample to a Population-based Sample of Adults who show Aggressive Behaviour

In order to compare the demographic profile of the present sample with a large sample of adults with ID and aggressive behaviour, a literature search was conducted to identify a published paper or report containing comparable sample information. Only one study was identified that provided demographic information on a population-based sample of individuals with ID and aggressive behaviour (Sigafoos et al, 1994). It is acknowledged that this paper is not recent and presents data on both children and adults in the community and in institutions in Queensland in Australia; however in the absence of a more appropriate paper, comparisons with this report are presented (see Table 3). As the study by Sigafoos et al (1994) included children, comparisons of age could not be made; similarly, as the study included individuals in institutions, comparisons of place of residence could not be made although it can be observed that the gender breakdown is similar.

Table 3: Sample Characteristics and Characteristics of a Large Sample of Adults with Aggressive Behaviour

Characteristic		Sample N=100 %	Sigafoos et al (1994) N=261 %
Gender	Male	63	64
	Female	37	36
Level of ID	Mild	23	8
	Moderate	32	31
	Severe/profound	45	54
	Unknown	-	6
Expressive verbal communication	Language	75	63
	No language	25	37

APPENDIX 19: CORRELATION MATRIX FOR RELATIONSHIPS BETWEEN THE SCORES ON THE MEASURES AT T1 (r_s values; N=99)

	MOAS	ABC-I	ABC-L	ABC-S	ABC-H	ABC-IS	QoL	Carer's Uplift	Carer's Burden
MOAS	-	-	-	-	-	-	-	-	-
ABC-I[a]	.77***	-	-	-	-	-	-	-	-
ABC-L[a]	.25*	.34***	-	-	-	-	-	-	-
ABC-S[a]	.36***	.44***	.53***	-	-	-	-	-	-
ABC-H[a]	.49***	.56***	.37***	.41***	-	-	-	-	-
ABC-IS[a]	.10	.26**	.15	.15	.37***	-	-	-	-
QoL	-.22*	-.18	-.42***	-.31**	-.26*	-.26*	-	-	-
Carer's Uplift[b]	-.32*	-.50***	-.17	-.25	-.31*	-.31*	.30	-	-
Carer's Burden[b]	.50***	.60***	.34*	.44**	.37*	.37*	-.20	-.67***	-
Carer's Concern	.39***	.46***	.37***	.26**	.47***	.47*	-.39***	-.32*	.58***

ABC-I: ABC-Irritability; ABC-L: ABC-Lethargy/social withdrawal; ABC-S: ABC-Stereotypic behaviour; ABC-H: ABC-Hyperactivity/non-compliance; ABC-IS: ABC-Inappropriate speech; QoL: Quality of life.

[a] Data not available for all participants.

[b] Family carers only.

*Significant relationship at the p≤0.05 level.

**Significant relationship at the p≤0.01 level.

**Significant relationship at the p≤0.001 level.

APPENDIX 20: ADDITIONAL TABLES FOR CHAPTER 5 –

INDIVIDUAL ASSOCIATIONS WITH AGGRESSIVE BEHAVOUR

Relationships with Participant Characteristics at T1

Table 1: Severity of aggression scores at T1 for each participant characteristic (N=96)[a]

Participant characteristic		**ABC-I score mean (SD)**
Place of residence[b]	Family home (n=39)	17.28 (9.62)
	Community group home (n=56)	13.98 (8.43)
Gender	Male (n=63)	13.62 (8.84)
	Female (n=37)	16.83 (9.40)
Level of ID	Mild-Moderate (n=55)	14.48 (8.69)
	Severe-Profound (n=45)	15.23 (9.72)
Age of participant[a]	Younger (18-37 years) (n=54)	15.76 (9.97)
	Older (38+ years) (n=44)	13.33 (7.94)
Expressive verbal communication	Uses spoken language (n=75)	14.54 (8.95)
	No language (n=25)	15.64 (9.79)

[a]Data were not available for all participants.

[b]5 Participants were excluded as they lived in their own homes as sole occupant, lived with their own family, or lived at residential college.

Table 2: Proportions of participants displaying each type of aggressive behaviour at T1 for each participant characteristic (N=99)[a]

Participant characteristic		**% with type of behaviour present**			
		VA	**PD**	**SIB**	**PO**
Place of residence[b]	Family home (n=39)	81.6	60.5	39.5	39.5
	Community group home (n=56)	76.8	53.6	44.6	44.6
Gender	Male (n=63)	68.3	52.4	41.3	34.9
	Female (n=37)	91.7**	58.3	44.4	52.8
Level of ID	Mild-moderate (n=55)	81.5	50.0	25.9	38.9
	Severe-profound (n=45)	71.1	60.0	62.2***	44.4
Age of participant[a]	Younger (18-37 years) (n=54)	75.5	52.8	43.4	35.8
	Older (38+ years) (n=44)	77.3	54.5	42.3	47.7
Expressive verbal communication	Uses spoken language (n=75)	77.0	54.1	32.4	40.5
	No language (n=25)	76.0	56.0	72.0***	44.0

VA: Verbal Aggression; PD: Property Destruction; SIB: Self-Injurious Behaviour; PO: Physical aggression to Others

[a]Data were not available for all participants.

[b]5 Participants were excluded as they lived in their own homes as sole occupant, lived with their own family, or lived at residential college.

**Significant association at the $p<0.01$ level.

***Significant association at the $p\leq0.001$ level.

Relationships with Co-morbid Diagnoses/Medical Conditions at T1

Table 3: Severity of aggression scores at T1 for each co-morbid diagnosis/medical condition (N=96)[a]

Participant characteristic/ co-morbidity		ABC-I score mean (SD)
Diagnosis of epilepsy	No (n=69)	15.52 (9.33)
	Yes (n=31)	13.21 (8.62)
Presence of physical disabilities	No (n=73)	14.33 (9.17)
	Yes (n=27)	16.07 (9.09)
Presence of psychiatric condition	No (n=43)	12.00 (8.54)
	Yes (n=57)	17.02 (9.05)**
Presence of anxiety disorder	No (n=70)	13.33 (8.97)
	Yes (n=30)	18.28 (8.71)*
Presence of obsessive compulsive disorder	No (n=74)	14.61 (9.07)
	Yes (n=26)	15.44 (9.49)
Presence of autism spectrum disorder	No (n=75)	13.42 (9.06)
	Yes (n=24)	19.04 (8.34)**
Physical health condition: obesity/overweight	No (n=30)	15.08 (9.64)
	Yes (n=70)	14.27 (7.90)
Physical health condition: gastrointestinal problems	No (n=27)	15.24 (8.95)
	Yes (n=73)	13.69 (9.72)
Physical health condition: skin problems	No (n=23)	14.96 (9.27)
	Yes (n=77)	14.33 (8.83)

[a]Data were not available for all participants.

*Significant association at the p≤0.05 level.

**Significant association at the p≤0.01 level.

Table 4: Proportions of participants displaying each type of aggressive behaviour at T1 for each co-morbid diagnosis/medical condition (N=99)[a]

Participant characteristic/ co-morbidity		% with type of behaviour present			
		VA	PD	SIB	PO
Diagnosis of epilepsy	No (n=69)	75.4	59.4	47.8	40.6
	Yes (n=31)	80.0	53.3	30.0	43.3
Presence of physical disabilities	No (n=73)	75.0	58.3	38.9	38.9
	Yes (n=27)	81.5	44.4	51.9	48.1
Presence of psychiatric condition	No (n=43)	69.8	48.8	32.6	41.9
	Yes (n=57)	82.1	58.9	50.0	41.1
Presence of anxiety disorder	No (n=70)	72.5	50.7	37.7	36.2
	Yes (n=30)	86.7	63.3	53.3	53.3
Presence of obsessive compulsive disorder	No (n=74)	74.3	54.1	40.5	44.6
	Yes (n=26)	84.0	56.0	48.0	32.0
Presence of autism spectrum disorder[a]	No (n=75)	77.0	50.0	35.1	36.5
	Yes (n=24)	75.0	66.7	62.5*	54.2
Physical health condition: obesity/overweight	No (n=30)	75.4	49.3	46.4	40.6
	Yes (n=70)	80.0	66.7	33.3	43.3
Physical health condition: gastrointestinal problems	No (n=27)	73.6	62.5**	41.7	40.3
	Yes (n=73)	85.2	33.3	44.4	44.4
Physical health condition: skin problems	No (n=23)	77.6	61.8**	44.7	42.1
	Yes (n=77)	73.9	30.4	34.8	39.1

VA: Verbal Aggression; PD: Property Destruction; SIB: Self-Injurious Behaviour; PO: Physical Aggression to Others

[a] Data were not available for all participants.

*Significant association at the p<0.05 level.

**Significant association at the p<0.01 level.

Relationships with Other Problem Behaviour at T1

Table 5: Correlations between Presence of each type of aggressive behaviour at T1 and severity of other problem behaviour (N=96[a], r_{pb})

ABC Subscale	VA	PD	SIB	PO
ABC-Lethargy, social withdrawal	.02	.20*	.09	.26*
ABC-Stereotypic behaviour	.18	.24*	.30**	.27**
ABC-Hyperactivity, non-compliance	.21*	.37**	.06	.40**
ABC-Inappropriate speech	.19	.21*	-.05	.19

VA: Verbal Aggression; PD: Property Destruction; SIB: Self-Injurious Behaviour; PO: Physical Aggression to Others

[a] Data were not available for all participants.

*Significant association at the p<0.05 level.

**Significant association at the p<0.01 level.

APPENDIX 21: TRIGGERS AND MOTIVATIONS FOR AGGRESSIVE BEHAVIOUR – A POTENTIAL CHECKLIST FOR CARERS

What triggers or motivates the aggressive behaviour?

External Environment

Physical Environment

Visual
- Things on TV/video e.g. violence, boxing
- Pictures of things
- Seeing play fighting and boxing
- Seeing certain things e.g. breakdown vans and ambulances
- Flashing lights e.g. fireworks
- Seeing people wear certain colours/people in uniform

Auditory
- Noise
- Loud noises/excessive noise
- People being noisy/loud people/noisy children/noise during staff change over
- Unpredictable/unexpected noises e.g. fireworks, coughing and sneezing
- Ambulance sirens
- Loud repetitive music

Spatial
- People invading personal space/people coming too close e.g. during personal care
- Physical contact/being touched
- Large groups
- Crowds
- Busy places/environments e.g. shopping centres, during staff change over, at day centre or at the residential home
- Hustle and bustle
- Being away from home
- Being in the car

Social Environment

- Other residents visiting home
- Other service users in the home – friction/living with others/other's aggressive behaviour/other people getting anxious or being aroused
- Exercising dominance/authority over other service users
- Retaliation
- Presence of female staff/younger staff/new staff
- Certain staff members
- Attention seeking e.g. when other people visit home/when carer talks to someone else
- Feeling ignored/not getting enough attention/when attention directed elsewhere
- Feeling left out
- Needing assistance

- Jealousy over others getting attention
- Seeking interaction
- Feeling not getting enough attention e.g. at meal times
- Others getting more attention
- Wanting attention from male service users
- When a parent goes out
- Family visits
- Difficult relationships with family/arguments with family and partners
- Sense of family rejection/lack of family visits/jealousy over others seeing family
- Getting a reaction
- Confrontation/conflict
- People saying something in ‘the wrong way’
- Hostile people
- Others in conflict e.g. hearing parents argue
- Being ‘told off’/bossed around/accused of lying/speaking to the person in the wrong way
- Lies being exposed
- Being told they have done something wrong
- Criticism/feeling ‘talked down to’/feeling nagged/being corrected
- Hearing people talk about them
- Taking exception to something someone says or to other people
- Someone irritating
- Feeling punished
- People staring
- Engaging them in lots of conversation

Internal Environment

Aversive Physical States

- Hunger
- Thirst
- Pain
- Discomfort
- Feeling tired
- Feeling poorly or when unwell
- After meals – feeling bloated
- Feeling too hot
- Not being clean after going to the toilet

Medical Conditions

- Increased aggression around a seizure or absences linked to epilepsy
- The menopause
- Premenstrual tension (PMT)
- Linked to hormonal contraception
- Constipation
- Irritable bowel syndrome
- Urinary tract infections (UTIs)
- Hyper or hypo related to diabetes

- Dental conditions
- Being low on oxygen, in relation to emphysema

Mental Health Problems

- Linked to a deterioration in mental health
- Linked to manic/elevated mood and hypomanic episodes
- Psychotic episodes, especially hallucinations and delusions
- Paranoia - thinking others are talking/spying/staring or looking at them
- Related to depression
- OCD
- Low self-confidence and self-esteem

Emotional States

- Anxiety
- Excitement
- Anticipation
- Feeling under pressure
- Feeling stressed
- Feeling distressed
- Feeling sad
- Feeling fed up
- When in a bad mood or temper
- Mood swings, mood-dependent behaviour
- Jealousy
- Anger
- Boredom
- Feeling insecure
- Agitation
- Frustration
- Feeling unhappy or upset
- Feeling sensitive
- Feeling embarrassed or they have made a fool of themselves
- Feeling over-aroused emotionally
- Feeling out of control
- When worried about things
- Feeling frightened

Expression of Volition

Goal-directed Behaviour

- Wanting demands met
- Task avoidance/to get out of doing something
- To get own way

Limits to Volition

- Demands not being met/satisfied
- Requests being turned down/denied
- Refusing demands
- Not getting what they want straight away/immediately/quickly
- Not getting own way
- Oppositional behaviour
- The word ‘no’
- Answers to questions not being what is wanted/not getting the wanted response
- When they cannot do something they want to do
- Not being able to go out when they want to
- Making demands to do something
- Making requests/encouraging to do something does not want to e.g. household duties
- Asking them to do something/an activity
- Difficulties with authority and following instructions
- If they cannot get their own way
- Feeling controlled
- Needs not being met

Characteristics of ID

Problems with Adaptability/uncertainty

- Any changes
- Inconsistency in management
- Changes to routine/plans
- People not following rules/things they do not class as ‘normal’
- ‘Black and white’ view of the World
- Unexpected events
- Unpredictability/surprises
- Unplanned changes
- Impatience/waiting for things
- Queuing
- Strangers/new people
- New places/environments
- New activities
- Needs to know what they are doing and with who
- Objects being moved around house/needs to know where everything is
- Changes to surroundings
- Needs to know what is happening
- Changes in care staff
- The transition between events e.g. returning from day centre
- Things not meeting expectations
- Christmas – this can be difficult due to all the changes in routine
- Compulsions – when cannot complete the compulsive task
- Interruptions to obsessional or ritualistic activities

Communication Difficulties

- People not understanding them
- Difficulty trying to get people to understand them
- Others not understanding them/not understanding requests
- When they do not understand what others are saying
- Communication frustration
- Behaviour is communication/their aggression is communicative
- To indicate a need due to communication difficulties

Specific Activities/events

Specific Activities

- Going to the doctors
- Going to the dentists
- Going to chiropody
- Appointments
- Administering medications
- Personal care –e.g. bathing, combing hair/being dressed/undressed/cutting nails/shaving
- Personal hygiene
- Mornings/getting up
- Getting reading in mornings
- After meals

Specific Events

- Christmas
- Build up to special occasions/visits/holidays
- Abuse – traumatic life events
- Birthdays
- New Year

Predictability of Behaviour

- Would you rate the aggressive behaviour as unpredictable?