Handbook of autism and education: Chapter 31 Behavioural Issues and Supports

Andrew A McDonnell BSc., MSc., PhD. Clinical Psychologist, Director of Studio3 Training Systems. Minerva Mill, Station Rd, Alcester, UK, B49 5ET.

Michael McCreadie, B.Sc., P.G.C.E., Dip S.L., M.Phil., M.Sc., D.Phil. Health Psychologist, Studio3 Clinical Services. Minerva Mill, Station Rd, Alcester, UK, B49 5ET.

Paul Dickinson BSc. M.A. M.Sc. C.Psychol. Clinical Psychologist, Studio3 Clinical Services. Minerva Mill, Station Rd, Alcester, UK, B49 5ET.

<u>Introduction</u>

Parents, carers and staff supporting people with autism, may experience behaviours that can be intense and even frightening. These can occur in a variety of settings; home, school and adult care services to list just three examples. Being diagnosed with autism is a 'risk marker' for exhibiting behaviours of concern in people with intellectual disabilities (ID) (McClintock et al., 2003) and this behaviour is more serious in people with autism in addition to ID (Matson and Rivet 2008).

It is not uncommon that communication/social reciprocity and restrictive interests which are core features of autism underlie many of the behaviours that others find distressing or challenging. Terms like 'meltdown', or 'outburst have been used as descriptors that include a wide range of behaviour such as aggression to self, others or property or significant distress associated with high levels of anxiety.

There is a clear need for effective and safe behaviour management strategies. Behavioural approaches have often been drawn upon and are far from being a new concept in autism. In 1949, Fuller published one of the first articles on using behavioural technology to shape an arm movement response.

In this chapter, the authors will concentrate on several specific areas that are emerging as important concepts within the literature for children and young people with autism who present with behavioural issues. The discussion will include; the significance of terminology, parent, family and carer supports, the emerging influence of positive psychology and stress, training and behaviour supports, high risk behaviours of concern, evidence-based reactive methods, and paradigm changes. Within this wider overview there will be an emphasis on the importance and utility of a *holistic* approach that is also *individualised*, as the foundation of any attempt to support people with autism who show behaviour that may be a risk to themselves or others, or reduce the opportunity for a positive social presence.

<u>What is our understanding of autism?</u>

Any discussion of behavioural issues and supports needs to consider current understandings of autism. How autism is understood will invariably impact on the nature of interventions and the way they are delivered. A number of the key principles that underpin the authors' theoretical framework and value base have been outlined in articles by McDonnell and Gayson (2014), McCreadie and McDermott (2014). The reader is referred to these papers for fuller details, but integral to the authors' perspectives are a number of key elements:

An approach based on developmental difference

Key to service design within this framework is *individualisation* that is underpinned by (as far as possible) and appreciation of the service user's perspective, the perspective of the autistic person. The authors propose that this reflects a non-medical model, that recognises autism as

part of a wider picture of developmental and neurodevelopmental diversity. The model of support and service provision is different therefore from one based on a treatment modality, drawing on a theoretical framework that sees autism, or the particular behaviours associated with autism as a pathology requiring treatment (Milton, 2012).

Supporting and empowering the individual, not changing the individual

A perspective that views autism as developmental difference rather than a disorder requiring remediation or treatment, leads the authors would argue, to approaches focusing on the individual with autism and enabling and empowering them to function as well as possible and enjoy the best quality of life possible. This is at the heart of the philosophy of Studio3 the organisation where the three authors work. The value base that sees autism as developmental difference, as opposed to 'disorder' or pathology requiring remediation and treatment, distinguishes approaches centred on the individual and their perspective, from those seeking to change the individual, and in particular those aspects of their presentation that are not developmentally normative. While we acknowledge the field of Applied Behavioural Analysis approaches to autism has developed and diversified considerably in the 30 years since Lovaas' 1987 paper, we would contend that its origins are in a perspective that sought to make the person with autism 'indistinguishable' from 'normally functioning peers', as such its perspective was one of seeing autism as a disorder. An individualised approach to developmental difference is in stark contrast to this, even if the tools of Applied Behavioural Analysis may form part of the approach to supporting the individual.

Moving away from a deficit model

Theoretical models of autism arising from cognitive psychology such as Theory of Mind (Baron Cohen, 2000) or Weak Central Coherence (Frith 2003), can also focus on the perceived deficits in the functioning of the autistic person, describing them as 'lacking in empathy' or 'aloof'. Researchers and academics in the field of autism who are autistic themselves have challenged such deficit based language and formulations. Milton (2012) for example, has argued the true difficulty in relating between the autistic and 'neurotypical' communities is one of 'double empathy'. Neurotypical individuals, including care, education and health professionals struggle to empathise with the experience of the autistic person, and label behaviour that is functional for the autistic person as pathological and in need of remediation, or as 'interfering with learning'. As Vermuelen (2012) has argued, the task of the professional helper is to empower the autistic person to function within our, chaotic neurotypical world.

Behaviour supports informed by developmental difference

Key to the value base and theoretical framework of Studio3's approach to what we will term 'behaviour of concern' (for further discussion see below) is a holistic perspective that normalises or rather 'de-pathologises' behaviours that are experienced as challenging by individuals and services. Such behaviours are viewed rather as having important functions for

the autistic person, and in some cases are for them an understandable or even rationale response to the chaotic, over demanding and unpredictable neurotypical world.

Sensory Issues

Relationship between sensory issues and Behaviour of Concern

Sensory differences in individuals with autism are increasingly being reported by researchers. Kern et al. (2006) used the sensory profile (Dunn, 1997) and found that there were differences in auditory, visual, touch, and oral sensory processing between participants with autism matched with a control group of persons without autism. Baranek et al. (2006) and Cheung and Siu (2009) identified that children with autism have different responses to sensory stimuli and identified they can be hypersensitive to sound.

There are also accounts of sensory difference that have been reported by authors who self-describe as autistic (see Grandin, 2006; Grandin and Scariano, 1986; O'Neil and Jones, 1997; Mukhopaday, 2003). O'Neil and Jones (1997), examined personal accounts of people with autism and they identified various sensory-perceptual abnormalities. These included: hyper – and hyposensitivity, sensory distortion, overload, multi-channel receptivity, and processing difficulties. Grandin (2006), reported that sudden loud noises hurt her ears, likening the experience to a dentist's drill hitting a nerve (Grandin 2006) she also argued that her fear of a noise was a factor for her challenging behaviour.

There has been much research on theoretical concepts relating to the sensory processing differences experienced by autistic people (see discussion by McDonnell et al 2015). Clearly, both research and the narrative accounts of autistic people have contributed to practitioner knowledge and understanding. The increasing importance of sensory issues in academic and professional consciousness is reflected in their inclusion in the diagnostic criteria for autism in DSM-V (see also Wiggins et al. 2009 and O'Brien et al. 2009). Research into sensory based interventions for children has not produced positive outcomes, although many of the studies do show a lack of academic rigour (Case-Smith, Weaver and Fristad, 2015).

Notwithstanding the above, in the authors experience the language around sensory issues in relation to behaviour support tends to focus on negative aspects, particularly with respect to sensory processing differences being characterised as triggers for behaviour of concern or barriers to inclusion or learning in mainstream environments (e.g. primary school classrooms). Based on our experience we would urge consideration of drawing on Positive Psychological approaches (these will be discussed further below). Such a framework would focus on sensory 'strengths' rather than sensory challenges in the development of Behaviour Support Plans. We refer the reader to a recent publication by Milton, Mills and Jones (2016), where is highlighted that behaviours that are in reality positive sensory coping strategies for individuals, may be described negatively as 'stereotypical' or 'stimming'. The authors propose a holistically informed Behaviour Support Plan will include consideration of the utility of sensory coping

strategies for the autistic individual, especially when they experience stress in the context of elevated levels of demands being made upon them.

Terminology

When reviewing the published literature on behavioural supports, there are terminological differences that can be confusing for the reader. Terminology is also influenced by the philosophy of approaches. As Boroditsky, (2012) argues language is often associated with differing thought processes between cultures, this is no less true of different communities within the academic study of autism and professional groups that work with autistic people with autism. There are many terms which are used that clearly have an influence on the perception of people with autism by families, professionals and educators; for example the terms such as 'intervention and treatment'. In the case of the terms Applied Behaviour Analysis (ABA) and Positive Behaviour Supports (PBS) sometimes heated and vitriolic debates persist in the literature (see Keenan et al. 2014). A more positive dialogue between the proponents of different approaches may promote greater mutual understanding and perhaps even richer holistic approaches. In this chapter the term 'behaviour supports' will be used in a generic sense. The reason for this is to avoid the use of over technical jargon.

Labelling theory also indicates that terminology changes can have a positive impact. In terms of behaviours of concern, a variety of labels have been adopted often with negative connotations, these include: problem, problematic and/or disruptive behaviour. The authors propose that these labels unhelpfully focus on the child as an object that has the problem that needs remediating, rather than reflecting the complexity of behavioural issues and their interaction with the *environment*. It is in the authors' experience, often the environment that needs appropriately adapting if behaviour of concern is to be reduced in the longer term.

In more recent history, terminology that stressed the challenge to services of particular behaviour of concern began to be utilised. **Blunden and Allen (1987)** first adopted the term *challenging behaviou*r. It was defined as: *"Culturally, abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities"* (Pp. 4-5).

This change in terminology has arguably led to a change of emphasis on broader *contextual* variables (i.e., carer behaviour, organizational factors). Critics of the term challenging behaviour have argued that the term can lead to labelling, stereotyping and diagnostic overshadowing (Chan et al., 2012). The authors of this article argue that the term 'challenging behaviour' should be replaced with *'behaviour of concern'* to highlight the ideal *response* of support staff, rather than the challenge they must overcome. The term *behaviours of concern* will be adopted for the remainder of this chapter (Chan et al., 2012).

 The apparent Applied Behaviour Analysis Verses Positive Behaviour Support debate

One of the problems that lies in the background of this debate is that there are differences in definitions of Positive Behaviour Support (PBS) (Gore et al., 2013). It must also be acknowledged that those who advocate a PBS approach, argue that it is 'data driven' and such language appears in various definitions (Allen, Kaye, Horwood, Gray and Mines, 2012). Such an emphasis on data reflects the ongoing use of Applied Behaviour Analysis (ABA) methodology within PBS approaches, indeed one might argue that it is disingenuous to suggest that PBS makes no use of ABA, given that detailed behavioural observation and assessment, in particular Functional Analysis are fundamental components of a thorough PBS plan.

Much discussion of the use of PBS has centred on its application to adult social care and related settings providing for people with Intellectual Disabilities. Much has been made of its application as a 'whole organisation approach. **Bradhsaw et al (2010)** published a paper that evaluated the use of a schoolwide PBS approach, and reported its efficacy in reducing behaviour of concern, including that shown by pupils with more complex needs. The authors suggest more research in this area is needed, particularly in relation to UK special and mainstream education settings.

Notwithstanding what has been at times an intense and vitriolic debate, the significant contributions made by approaches arising from behavioural psychology should be acknowledged. Key among these have been certain core values that emphasise the role of the environment, including those persons interacting with the individual with autism in the genesis and maintenance of Behaviour of Concern. Such developments have helped challenge the notion that behaviour of concern arises purely out of deficit or pathology 'within then person', when almost invariably the environment has a significant role. A thorough Behaviour Support Plan, will address any necessary modifications to the environment necessary to support the autistic person's developmental difference and facilitate their inclusion.

The authors would argue that 'purist' behavioural approaches have a specific weakness, in that they fail to acknowledge of the importance of the relationship between the person delivering the intervention and the person receiving it. Difficulties in replicating outcomes are often explained by referring to inadequate training in the approach concerned, or indeed lack of adequate understanding of the theory underlying such approaches, on the part of those critical of 'purist' interventions (see Keenan et al 2014). The authors would propose this stems from an emphasis on behavioural approaches as a technology. Previous large scale meta-reviews of outcome studies of a wide range of therapies demonstrated the relationship of the therapist - person was critical (Roth and Fonagy 2005).

Within the literature there appears to be limited acceptance that implementation issues are often significant in the use of ABA or PBS approaches in schools (Ackerman et al., 2010) or the teaching staff or family carer called upon to work to a behaviour support plan based on a ABA or PBS approach, the implementation of the plan within the environment they are working is of key concern. Core dominant themes to improve implementation include consistency and adaptability, rewards, evidence-based decision making and professional development and support (Ackerman et al., 2010). The authors would also add additional areas that include good quality reactive advice and training (McDonnell, 2010) and the relationship between the

behaviour advisor and the people they support. There is an issue with advisors providing consultation 'at a distance', in the authors opinion role modelling, coaching and feedback are critical elements of enhancing application (Robin et al., 2005).

From the perspective of the practitioner in Education, supporting individuals with autism and the staff that work with them, a rapprochement based on areas of agreement between pure ABA and PBS approaches would be helpful, alongside more applied research that focuses on the challenges of implementation in 'real world settings'.

The intensity of behaviours of concern
When examining the prevalence of behaviours of concern, many figures tend to focus on the *minority* of people with a diagnosis with intellectual disabilities. Prevalence of behaviours of concern amongst individuals with intellectual disabilities as well as autism; vary between 8% and 38% (Emerson et al., 2001; Kiernan and Qureshi, 1986; Murphy and Wilson, 1985; Wallander et al., 2003). UK research reports that the prevalence rate of behaviours of concern and mental ill health among people with intellectual disability is between 16-41% in an adult population (Cooper et al., 2007).

The *frequency* of behaviours of concern show considerable variation (Lambrechts and Maes, 2009). Our experience of behaviours of concern has a highly *subjective* component. People may describe and interpret the same event from very different perspectives. For example, we may experience extremely *intense* behaviours that are *low* in frequency and interpret them inconsistently. This may be particularly likely for the less serious and repetitive behaviour types (McGill et al., 2001).

Lambrechts and Maes (2009) suggested staff characteristics that influence rates of reporting of behaviours of concern, included attributing these to 'internal' rather than environmental factors that impact on service users. In considering this, it is important to accurately assess the *intensity* of incidents as well as their *frequency* when we are considering the level of *risk* a particular pattern of behaviour may be presenting. Episodic severity (LaVigna et al, 2016) is a measure where the intensity *and* gravity of an incident can be measured. This is particularly important when considering behaviours in adolescents that may be 'anti-social' but not life threatening. In contrast, a person may present with very *low* frequency behaviours of concern with potentially life threatening consequences. In sum, intensity is clearly a measure that requires further investigation by researchers. As practitioners, it has been the authors' experiences that paradoxically interpreting and analysing behaviours of concern we may overly dwell on *negative* experiences. We often do not pay enough attention to the *positive* experiences that people have and this can create the illusion that a person's behaviour is more challenging than the reality. There is a growing body of research in the field of positive psychology, which may be of great benefit to practitioners.

The emergence of positive psychology

There is an emerging influence of positive psychology within the field of autism and behavioural supports, which is currently at quite an early stage of development. Analysing the impact of *positive interactions* can be an extremely powerful tool.

The more modern use of the term positive psychology emerged from the growing literature on wellbeing and happiness. A focus on *strengths* rather than deficits is the basis of the approach. Seligman and Csikzentmihayli (2000) argued that the 'old' psychological thinking was mostly focused on negative characteristics.

> "It concentrates on repairing damage within a disease model of human functioning. This almost exclusive attention to pathology neglects the fulfilled individual and the thriving community. The aim of positive psychology is to begin to catalyse a change in the focus of psychology from preoccupation only with repairing the worst things in life to also building positive qualities" (Seligman and Csikszentmihalyi, 2000, p.5).

A good working definition was proposed by the Irish Psychologist Alan Carr:

> "Positive psychology is concerned with the pleasant life, the engaged life and the meaningful life" (Carr, 2011, p.2).

In terms of behaviours of concern this may represent a stronger focus on *skill acquisition* and *building resilience* through developing better coping strategies for people with autism and their supporters. This approach entails a more *holistic* overview of the person rather than focusing on a collection of behaviours that require 'fixing' or 'repairing'. Such a holistic view inherently considers the interaction of the person with their *environment*, and accepts that other people including staff and carers are *part* of that environment.

In education research, there has been an emphasis on the development of resilience based programmes to target primarily childhood mental health issues which include depression. (Seligman et al., 2009; Norrish et al., 2013). The authors can find little research however that includes children with autism. Notwithstanding the current paucity of research, the potential usefulness of Positive Psychology in supporting autistic children and young people has been embraced by some authors. In the last six years, Groden et al (2011) published a book dedicated to this approach that explores the use of Positive Psychology informed strategies to build resilience, increase optimism and self-efficacy (among other areas of functioning).

There authors contend there are many potential areas of application of positive psychological thinking to behaviour supports. These areas could include focusing on understanding individuals with autism who appear to manage their own behaviour, and a placing greater emphasis on resilience. There is a clear need for the development of what has been loosely described as positive psychological techniques for supporting children with autism. One key implication of adopting a positive psychology approach could be in the way behaviours of concern are recorded. Carers or supporters are often expected to record *incidents*. This can be

a negative process where there is a strong emphasis on *risk* and *reactive* behaviours. A focus on *positive* recording of data (what has gone well, and why that might have been) rather than an overemphasis on recording negative behaviours can be achieved by using the same recording systems, but intermittently targeting positive behaviours. Monitoring positive emotions such as moments of happiness, or positive interactions may help to enhance interventions.

A greater understanding of stress and behaviour of concern

Stress, anxiety and trauma have been proposed as potentially significant factors in behaviours of concern of people with ASD (Lipsky, 2011; Bradley and Caldwell, 2013, McCreadie and McDernott, 2014). While the term anxiety is used widely in the autism literature (Attwood, 2007) stress is used much less, but the construct is much broader and focuses more on transactional processes. Lazarus and Folkman's (1984) description of a transactional model of stress emphasises *interaction* between an individual and his/her environment. Stress occurs when the demands of stressors outweigh coping responses and there is a clear interaction between environmental and physiological events. Implicit in this model is the *cognitive appraisal* of threat as some individuals with ASD have difficulties in regulating their emotional responses and communicating them (Frith, 2003).

An understanding that the autistic person may experience the neurotypical world as chaotic, demanding and *stressful* is at the heart of much of the work done by the authors through Studio 3. A formulation arising from an understanding of *what* components of the person's environment and their interaction are particularly stressful for them, and the coping mechanisms they utilise (including behaviour of concern), are critical underpinnings of any support plan.

Individual's coping responses are important in our understanding of stress, as it is almost impossible in the modern world to be 'stress free'. It is our coping responses that determine how we adapt to stress. Many people with autism have few 'coping tools'. Some restricted or repetitive behaviours may have very real coping functions. For example, a person may engage in stereotyped movements which actually help them to regulate their arousal (McDonnell and Gayson, 2014). We need to consider carefully therefore, our own perspectives on such behaviour. Interventions that attempt to reduce certain types of restricted, repetitive or stereotyped behaviour because *we* perceive them as 'abnormal', may in reality be taking away one of a person's coping mechanisms without providing them with an effective alternative.

Key to Studio3's approach, particularly in managing behavioural 'crises' is the concept of 'Low Arousal' (or L.A.). Integral to this is the notion of *reducing* demands that are sources of stress for the individual and enabling them to deploy coping mechanisms that support effective *self-regulation*. This may seem counterintuitive, especially as it may involve 'allowing' a person to engage in periods of repetitive behaviour, but is based on an understanding of how the individual may use such behaviour to enter 'flow states' that are associated with decreased

arousal and reduced, measurable physiological indicators of stress (such as heart rate). The L.A. framework draws heavily on Seligmann's so called PERMA model. For further reading and explanation of this approach the reader is referred to McDonnell and Gayson (2014).

Stress based interventions can focus on the child, the carer or the wider organisational context (such as a school or college environment). Transactional models of stress may be important when examining behaviours of concern (McDonnell et al., 2015). This is especially true for parents, family members and carers who are faced with behaviours of concern on a regular basis and their level of stress impacts on their relationship with the individual with autism and the environment around them. Exploring stress as a key variable in behaviours of concern may require us to change emphasis. Currently, Positive Behaviour Support Plans are a mechanism for the implementation of supports for specific behaviour of concern (Albin et al., 1996; Carr et al., 2002, LaVigna and Donnellan, 1986; McClean, et al., 2005). Practitioners and researchers may want to consider adopting the language of stress within the PBS plans and related documentation. Would a *stress support plan* yield different ideas from a behaviour support plan? Would it provide 'surplus meaning'?

Parents, families and carers; a new way of framing the problem

The sources of stress on *parents* are varied and multiple, and include having to relate and interact with statutory and support agencies, deal with economic pressures, maintain the welfare of siblings, manage concerning behaviours presented by their child with autism, ensure the safety for their child with autism, as well as the day-to-day hassles of ordinary life (McCubbin et al., 1982). In addition to the unique pressures related to the nature of the disability itself (Hastings et al., 2005), parents of children with autism are confronted with the same systemic issues as parents of children with other disabilities. In their study of mothers of children with disability, Curran et al. (2001) estimated that following the birth of the child, 67% of mothers are unable to maintain paid employment, placing additional economic pressures on the family and potentially leading to mothers feeling more isolated.

The behaviours exhibited by children with autism not only place demands on their parents, but inevitably also places considerable strain on sibling relationships (Sanders and Morgan, 1997). Children with autism are more likely to have a restricted repertoire of play, poor eye contact and experience difficulties with joint attention which not only limits social responsiveness but can create further disruption to family life by impacting upon the quality of interaction with other children within the family (Harris, 1994; Knott et al., 1995; Sanders and Morgan, 1997). Furthermore, studies have suggested that siblings of children with autism can experience fear or be disturbed by their sibling's challenging behaviour (Bägenholm and Gillberg, 1991; Roeyers and Mycke, 1995). While studies examining the quality of relationships between siblings where one has autism has drawn conflicting conclusions (Fisman et al., 1996; Kaminsky and Dewey, 2001; McHale et al., 1986), there is general acknowledgement that parental stress is influenced by concern over the quality of interaction between siblings and anxiety over issues of welfare and safety for non-disabled siblings (Sherman 1988; Rousey et al., 1990; Bromley and Blacher 1991; Rojahn et al., 1991; Stoneman and Berman, 1993).

The concern for the welfare of non-disabled siblings relates to the most significant predictors of parental stress namely; behaviour, age and size (Tausig, 1985; Sherman, 1988; Rousey et al., 1990; Bromley and Blacher 1991; Kobe et al., 1991; Blacher et al., 1992). In their longitudinal study of 3-year olds with and without disabilities, which included children with autism, Baker et al. (2003) reported that when the influence of behaviour problems on parenting stress was accounted for, mental development explained no additional variance. Hastings, et al. (2005) observed that families and carers report significant stress in managing and responding to behaviour that is perceived as being anti-social.

In their study of life satisfaction in parents of children with autism, Milgram and Atzil (1988) found that parents did not relate life satisfaction to objective evaluations of their child's behaviour (as rated by teacher and psychologists), but rather to their ratings of their own parenting behaviours, such as level of parenting difficulty, proportion of parenting tasks and fairness. This suggests that while child behaviour may be a significant predictor of stress in parents, it is how the parent perceives their own role and behaviours that influences their own satisfaction.

Carers can experience strong emotional responses to behaviours of concern. A Swedish study reported high levels of anger experienced by staff after they were exposed to challenges (Lundstrom et al., 2007). In a qualitative Scottish study, staff who supported people with autism reported similar intense emotional reactions (McDonnell, 2010; Butrimaviciute and Grieve, 2014). Both studies were conducted in adult services, but, reflect the challenges people face. This is also reflected when working with families (Heilskov Elven, 2010; Woodcock and Page, 2010). A key theme from the literature is that the intensity of behaviours in one of the most important key issues (LaVigna et al., 2015). This is particularly true for teachers, parents and carers.

'Styles of thinking' also have an impact. The attributions people make regarding behaviour of concern e.g. what causes it, has been subject to considerable research. The results of attributional research have been inconsistent (Wilner, 2006). However, the attribution of 'controllability' or responsibility for behaviours of concern to service users has been shown to be reliably associated with significant staff factors. (Dagnan, Hull and McDonnell, 2013). In a recent review, Rose (2011) claimed there is increasing evidence to suggest that staff psychological factors, such as attitudes, can influence the efficacy of interventions for behaviours of concern.

High risk behaviours of concern

Behaviours of concern can include high risk behaviours where serious harm may occur to individuals. Autism has been identified as a risk marker for physical aggression (McClintock et al., 2003) and many intervention studies with children have focused on physical aggression (Horner et al., 2002).

We have identified two areas that can cause concern for researchers and practitioners, Self-Injurious Behaviours and forensic issues.

Self-Injurious Behaviours

Richards et al. (2016) in a carer self-report survey over a three-year period examined the persistence of SIB. They found 77.8% of behaviours had persisted. This clearly demonstrates the significant challenges that this form of behaviour concern presents.

Self-injurious behaviours can evoke strong emotional responses among care staff (Oliver, 1993) and appear to be associated with individuals with a diagnosis of autism (Rojahn, Schroeder and Hoch, 2008). Significant advances have been made in our understanding of the causes and function(s) of SIB (Iwata, et al, 1992; Rojahn et al., 2008). Behavioural models would suggest that behaviour may be reinforced by *extrinsic* sources of *positive reinforcement* such as attention, and negative reinforcement, such as escape from demands (Iwata et al., 1992) or that the behaviour may produce *intrinsic* reinforcement such as sensory stimulation or pain reduction (Rojahn et al., 2008).

In a study of overt signs of pain of a group of 35 people with intellectual disabilities and SIB matched with 35 controls, the SIB group had significantly more overall non-verbal pain signs relative to the matched comparison group on a global nonverbal pain measure (Symons, Devine and Oliver, 2012). There is clearly a complex pattern of interactions between the self-injurious behaviour and the experience of pain. For some individuals, pain mechanisms may reinforce SIB. There are also many other areas of complexity which need to be considered in the management of self-injurious behaviour, for example the relationship between SIB, self-stimulatory behaviours and sensory factors (Smith et al., 2005). Pain mechanisms may also impact other forms of information processing. Durso et al. (2015) in an exploratory study gave acetaminophen (Tylenol) to students and showed them pleasant as well as unpleasant stimuli. They claimed that the groups who received Tylenol showed moderated emotional responses to both stimuli. This study is limited, but it may suggest that emotional processing and pain pathways are associated in ways which could have an impact on behaviours of concern such as SIB.

Individuals with a severe/profound degree of ID are significantly more likely to show self-injury and stereotypy than individuals with a mild/moderate degree of ID (McClintock et al., 2003). There also appears to be a relationship between SIB and stereotypic behaviours. Clinically, the reduction of one behaviour can lead to an increase in the other. Individuals with deficits in receptive and expressive communication are significantly more likely to show self-injury (McClintock et al., 2003). Hall et al. (2013) in an innovative study of a person with Prader Willi Syndrome used heart rate activity levels to determine that the behaviour operated on principles of automatic reinforcement. The use of heart rate to measure arousal would appear to hold promise, especially with the advent of simple wearable technology.

In sum, SIB is a *multifaceted* and complex phenomenon, supporting these behaviours presents significant challenges for researchers and practitioners (McDonnell, 2010). Managing SIB is a *high-risk* process, especially when considering whether an intervention may *increase* the frequency or intensity of the behaviour in the short term (the 'extinction burst'). One fruitful area of investigation is the role of stress as a key variable (Romanczyk et al., 2012). The transactional nature of stress (Lazarus and Folkman, 1994) suggests that stress reduction for individuals *and* their carers may have heuristic value.

Forensic challenges

People on the spectrum can engage with high risk behaviours that can lead to an involvement with the police and the criminal justice system. A recent review of the literature identified a limited number of studies with a variety of methodologies (King and Murphy, 2014). Very few studies focused in children and adolescents. A UK interview study of 6 adults, who offend with a diagnosis, identified features of autism related to offending. These included social deficits susceptibility to life events and poor emotional coping strategies. Anecdotal evidence suggests that poor compliance with social rules is a critical factor. Managing and supporting such behaviours represents significant challenges for those involved in the development of PBS plans. The use of *educational* approaches may be of some benefit (Vermeulen, 2012).

Autism can also be associated with more extreme claims. **Allely et al., (2014**) conducted a retrospective review of cases of mass murder and serial killing, and found that 28% had definite or probable ASC, with 55% of these (and those with suspected head injury) having experienced *psychosocial stressors*. Therefore, these results tentatively suggest a significant number of mass murderers may have had neuro-developmental disorders, such as autism (or a head injury). Narrow post hoc studies such as these can create an '*illusory correlation*' that autism is linked strongly to crime; current data are less clear. Evidence is limited about prevalence rates of people with autism committing crimes (King and Murphy, 2014). Similarly, people with a diagnosis are involved in cybercrime, but, there is no current evidence to suggest that autism per se is a *risk marker* (Ledingham and Mills, 2015). A stronger argument is that for a significant number of people who may have a diagnosis, the need for *isolation* and the *avoidance* of social interaction may lead to the possibility of a reduced risk of criminal behaviour. A recent UK survey of adults with intellectual disabilities and autism would appear to provide 'soft evidence' for this claim (Beadle-Brown et al., 2014).

When interpreting prevalence studies, determining *causation* is also a critical issue. Our current research knowledge cannot answer some basic critical questions. Do people with autism commit crimes for what could be described as neurotypical reasons? Or are certain criminal behaviours more likely to occur to people with a diagnosis?

Behaviour supports for offending behaviours is a controversial area. Providing strategies to reduce offending behaviour is complex and multifaceted. The heterogeneous nature of autism necessitates supports that are highly individualised. When identifying goals for individuals

there can be difficulties with communicating the need for change as often people tend to see the world from their own perspective (Murphy, 2010). Perhaps the most realistic goal in such challenging cases is to identify *specific risk factors* and address how these can be managed by avoidance of known difficult situations alongside the development of improved *coping strategies*, with appropriate supervision. The above will be key components in managing risk in individuals with autism-spectrum conditions and forensic/offending histories.

Improving *coping responses* can include well tested strategies such as mindfulness based approaches. There is an emerging literature that these methods may be beneficial to people on the autism spectrum in assisting them to manage their stress (Spek et al., 2013; Singh et al., 2013; Singh et al., 2011).

Although research in terms of offending behaviour is limited; the challenge for professionals is to focus on behaviours that *minimise risk* rather than the teaching of social goals. Accommodating, autistic thinking in relation to crime requires a highly empathic approach from professionals. Criminal behaviours can lead to high degrees of enmity within communities. Whilst, autism should not become an excuse for criminally risky behaviours, understanding the individuals' perspectives can often clarify motivation. Furthermore, it could be argued that managing high risk behaviours needs to focus on what has been described a problem of 'double empathy' (Milton, 2012). That is, carers and supporters' 'perceptions' of behaviour is a critical element of developing good effective strategies. The first author is reminded of a teenager who collected specific sports trainers, he would often steal from school lockers. He appeared to understand that this was wrong, but, the *urge* to collect plus the opportunity led to numerous school sanctions and police involvement with little impact on the behaviour. Success occurred by serendipity when his 'special interest' focus changed to more innocuous objects of a much lower value. Interventions or in this case a 'non-intervention' that is developed from an 'autism informed' perspective are more likely to help develop support plans.

Low arousal approaches

Behaviours of concern can escalate and in those situations a 'situational response' (LaVigna and Willis, 2016) may be required. The distinction between proactive and reactive components of such responses would appear to be accepted in the literature (LaVigna and Donnellan, 1986). There has been an emerging literature that focuses on the development of evidenced based approaches to reactive strategies. In contrast to the focus on proactive behaviour supports, evidenced based crisis approaches are still limited (McDonnell, 2010).

Models of de-escalation are relatively poorly understood. Spicer and Crates (2016) identified functionally based and non-functionally based non-aversive reactive strategies. These included introducing stimuli such as diversion to a preferred activity to negative resolution, such moving away from the person or removing demands, in non-functional situations strategies breathing or relaxation injecting humour and stimulus change. The authors examined incident reports of 17 people. Judges rated strategies in terms of four categories (functional and non-functional

non-aversive strategies, aversive strategies and restrictive practices). The authors reported that aversive strategies led to *escalation* in 47% of incidents and restrictive strategies to escalation in 46%. In contrast, they reported *lower* figures for *non-aversive* strategies. In the case of functional strategies an escalation in 7% of incidents and *no* escalation when non-functional strategies were used. On a positive note, this study is one of the first that examines reactive strategies. However, it is limited by several factors including sample size and not enough investigation of specific strategies. In a retrospective study of 24 Behaviour support plans in Australia, *reduction* in restraint was reported at three-month implementation (Spicer and Crates, 2016). More recently, approaches based on arousal reduction collectively known as 'low arousal approaches' would appear to be increasing in popularity (McDonnell et al., 2015; McDonnell, 2010;Woodcock and Page, 2009; Heilskov Elven, 2010).

If some behaviours of concern are mediated by a *heightened* state of physiological arousal, (McDonnell et al., 2015) the reduction of this physiological arousal state should *reduce* challenging behaviours, at least in the short term. Low arousal approaches are strategies used to manage these crisis situations. McDonnell (2010), defined four key components of low arousal approaches. First, *decreasing* staff *demands and requests*, as to reduce potential points of conflict around an individual. Second, *avoidance* of potentially arousing *triggers*, e.g. direct eye contact, touch and removal of spectators to the incident. Third, the *avoidance of non-verbal behaviours that may lead to conflict*, e.g. aggressive postures and stances. Fourth, *challenging staff beliefs* about short term management of behaviours of concern.

A Low Arousal (L.A) methodology is informed by a by a number of key ideas, often arising from professional and clinical experience. McDonnell (2010) notes the importance of the idea of trauma in understanding the genesis (and indeed maintenance) of aggressive behaviour in care and related settings. This is especially pertinent in the to the experience of those autistic people with behaviour of concern who have had services, educational or social care, withdrawn (sometimes on multiple occasions) because of those services' inability to 'cope' with the individual's behaviour of concern. Woodcock and Page (2010) discusses the impact of such experiences from both the perspective of a parent and a young person.

In considering the development and nature of staff beliefs about behaviour of concern, the authors consider it essential to incorporate an understanding of the nature of *emotional contagion* within staff teams or groups. A negative understanding or discourse surrounding particular behaviour of concern, originating with an influential staff member/s (especially if that individual is seen as 'senior' and 'experienced') can have a significant impact. Addressing this phenomena is essential when working with organisations such as schools and social care settings and is often core to interventions undertaken by Studio3 (see Hejskov Elven 2010).

In a reformulated cognitive behavioural framework the four key areas of the L.A. approach are:

(a) the reduction of staff demands and requests in a crisis;

(b) the adoption of verbal and non-verbal strategies that avoids potentially arousing triggers (direct eye contact, touch, avoidance of non-verbal behaviours that may lead to conflict, aggressive postures, and stances);

(c) the exploration of staff beliefs about the short-term management of challenging behaviours;

(d) the provision of emotional support to staff working with challenging individuals.

Considering sensory differences, coping strategies and vulnerabilities and their relationship to the environment the autistic person finds themselves is also essential in developing a L.A. informed behaviour support plan.

A cognitive formulation of this model emphasizes the role of *staff* behaviour in the maintenance of aggressive behaviour, which has some support from the literature (Hastings, et al 2005; Hastings and Brown, 2002; Hastings and Remington, 1994; Taylor and Carr, 1992). In practice carers are encouraged to examine their own contribution to behaviour. *Reflective practice* (Schon, 1987) is a cornerstone of the approach.

Physiological arousal is not a new construct and has long been implicated in autistic spectrum disorders (Hutt et al., 1964). Arousal regulation issues have been the focus of several studies and reported unusual and mixed evidence. Jansen et al. (2006) compared adults with autism with neurotypical adults in their response to public speaking and found that individuals with autism showed decreased heart rate, but normal cortisol responses. Goodwin et al. (2006) compared children and reported higher baseline heart rates of ASD participants. Hirstein et al. (2001) reported unusually high and unusually low baseline skin conductance responses in autistic children compared to non-autistic controls. These differences require replication using larger samples but there is an intriguing possibility that there may be considerable variation in physiological reactivity of both autistic children and adults.

Jennett et al. (2011) investigated the relation between self-injury and arousal in an individual with autism under different conditions of restraint. When some form of restraint was used the heart rate of the individual remained close to the resting heart rate although, when this restraint was removed or signalled to be removed, the individual's heart rate increased dramatically within a short time period. This may suggest for some individuals the *positive impact* of *deep pressure* contact as reported by Temple Grandin (1992).

The *reduction* of staff demands and requests in a crisis is a key component of a low arousal approach (McDonnell et al., 2002; McDonnell et al., 1998) as a reduction in staff demands can lead to reductions in aggressive behaviour (Taylor and Carr, 1992). A possible negative effect on carers is to reinforce an avoidance model. Whilst an avoidance model should not be a long-term strategy to crises approaches, it may well be the most effective staff response. Task demands are a component of many interventions that adopt positive behavioural supports (Carr et al., 2002). Terms such as "strategic capitulation" (LaVigna, et al 2016) have been used to describe demand reduction in crisis situations. Demand reduction may be an effective component of reactive strategies (Spicer and Crates, 2016). However, it requires a change in behaviour of *carers* rather than the person with autism per se. Woodcock and Page (2010) note

that there are real challenges for carers in a L.A. approach as it requires them to identify and change core beliefs about behaviour such as "I shouldn't let X get away with it" or "X knows exactly what they are doing" (see Woodcock and Page p. 89).

The evidence for the efficacy of low arousal approaches is emerging but scarce. Although, concepts such as these would appear to have high 'face validity' the evidence base is currently still limited. This would appear to reflect a general weak evidence base for reactive strategies.

The use of *restraint* to manage the behaviour of children with autism is a key area. McGill et al. (2009) in a UK survey of 268 children with intellectual disability and/or autism reported that physical restraint was used as least monthly in 68% of cases. Allen et al. (2006) reported high levels of usage in a sample of families who supported individuals with behaviours of concern. Physical interventions can be associated with high levels of risk and their implementation can be problematic (Leadbetter, 2008) or be a precursor to other abuses (Baker and Allen, 2001).

Apart from strong moral arguments for avoiding restrictive physical interventions they remain in use, and there would appear to be some features of autism that add further contraindications (McDonnell et al., 2015). There appears to be a strong association between *physiological* arousal and *sensory* experiences of people with ASD (Liss et al., 2006) Developing an evidence base for their reduction is still in its infancy. Staff training that contains physical interventions have a limited evidence base in terms of their effectiveness in reducing usage (Allen, 2002; McDonnell, 2009; McDonnell, 2010). Varied outcome measures have been used including staff confidence (Allen and Tynan, 2000) and reductions in management difficulty (McDonnell et al., 2008). Research needs to evaluate the *effectiveness* of such training (Baker and Allen, 2016). Most training research tends to focus on staff with less evidence reported for teaching reactive strategies to families. This is surprising as family members are exposed to 'meltdowns' (Lipsky, 2011; Woodcock and Page, 2010). There needs to be stronger focus on the views of young people with autism about developing alternative practices for restraint. Finally, addressing developing 'restraint cultures' within services will require strong organisational messages (Deveau and McDonnell, 2009), emphasising a range of organisational variables including *practice leadership* (Deveau and McGill, 2016).

In sum, reactive strategies are poorly understood and require more extensive research (Allen and Baker, 2016). The literature tends to focus on a dichotomy. Proactive strategies, tend to be contrasted with restrictive interventions such as physical restraint. De-escalation strategies that are non-physical in nature still receive only a small focus in the literature. Developing strategies as alternatives to their usage is laudable. More focus is required into their *reduction* with a strong emphasis on developing non-aversive reactive strategies. The authors propose that low arousal approaches offer a positive alternative to restrictive interventions.

Towards an integrated approach for behaviour supports

There is clearly a need for behaviour supports to continue to evolve and develop. The debates surrounding certain schools of thought such as ABA and PBS tend to focus on both science and values. There has been a change in value base from the early days of interventions where debates about the use of punishment were intense and vitriolic (LaVigna and Donnellan. 1986; Guess et al., 1987). The present solution would appear to focus on a value base that is *both* constructional *and* more holistic in nature. There would also appear to be an area of agreement that evidenced based approaches to behaviour supports are needed (Keenan et al., 2014; Gore et al., 2013, LaVigna and Donnellan, 1986).

The nature and development of science in behaviour supports is an important issue. Kuhn, (1962) argued that science develops in stages; pre-paradigm, paradigm, crisis and revolution. In pre-paradigmatic science there are a range of competing theories, in the next stage which he calls 'normal science' a dominant approach emerges. *Where* to place behaviour supports research in the autism field is a matter of debate. In our view, we are at a crossroads between being a pre-paradigmatic stage and a 'normal science'. If we are to achieve a more advanced science, then a focus on areas of consensus both in methodology, terminology and values is needed. One obvious area involves the integration of research approaches. Encouraging better combined biological and behavioural measurement (McCormick, Hessl, Macari, Ozonoff, Green and Rogers, 2014; Hoch, Moore, McComas and Symons, 2010).

Conclusions

To understand the issues surrounding behaviour supports, the authors have chosen to adopt a perspective of key emerging issues in the field rather than 'regurgitating' the ABA PBS debate in detail. There are several clear themes to supporting behaviours of concern. A radical suggestion would be to rethink the *focus* of behaviour supports. One key area of focus, would involve a stronger emphasis on *wellbeing* and *coping*, and less on directly targeting behaviours of concern. Second, a significant change of emphasis, concentrating on the behaviour of *carers* and *families*. Thirdly, on more *holistic* models of wellbeing (Dodge et al., 2012), that focuses on developing *strengths* and fostering *resilience* (Seligman, 2011) and applying these frameworks to people with autism (McDonnell and Gayson, 2014). A critical element to this is the understanding of stress and more importantly positive coping responses. Approaches such as mindfulness are clearly elements of such a framework.

The relative lack of progress of reactive management research is still concerning, as people will often manage crises with restraint, if left with little or no alternative. A greater understanding of de-escalation strategies such as low arousal approaches (McDonnell, 2010) is required. In addition, areas such as SIB and forensic issues need a strong focus on the management of these behaviours and in risk-reduction if individuals are to be supported in non-secure, non-custodial settings.

The complexity of autism makes generic studies difficult to interpret. If there is a theme of this work, the *heterogeneity* of autism must be reflected in the development of behaviour supports and interventions. To a certain extent there is a *homogeneous* approach to autism research which leads to a technique orientated 'one shoe size fits all approach', with populations that are

similarly poorly defined. Important within this is the 'voice of our consumers' who provide a different and rich data set, for understanding the complex inter-relationships between autism and behaviours of concern.

The current positive psychological 'zeitgeist,' that in influencing other fields, is beginning to have an impact in the field of autism. The application of positive psychological principles to areas such as resilience and positive emotions is in its relative infancy (McDonnell and Gayson, 2014; Norrish et al., 2013). Variables such as 'happiness' need to be included in the approach (Vermeulen, 2014; Diener and Biswas Diener, 2008). What should be the emphasis of behaviour supports? Our challenge is to develop an integrated approach that combines, science, values and reflects the complexity of the subject matter. Most of all behaviour supports must be 'autism informed' and positive in their focus.

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