DOCTOR OF PHILOSOPHY

A total population study of challenging behaviour and evaluation of Positive Behavioural Support outcomes

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Award date:
2018

Awarding institution:
Bangor University

Prifysgol Bangor
Bangor University

A total population study of challenging behaviour and evaluation of Positive Behavioural Support outcomes.

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Thesis submitted to the School of Psychology, Bangor University, in partial fulfilment for the degree of Doctor of Philosophy

March 2018

Acknowledgments

I have been extremely fortunate to have been supervised by Vasiliki Totsika and Richard Hastings. They are experts in their field and I have benefited from their knowledge, patient support and encouragement. I am even more grateful that they retained this commitment even with the complexity of a university move. I am also fortunate to have had Sandy Toogood as supervisor. It was at a placement in Sandy's service in Wrexham 15 years ago that my education into PBS began and he remains an inspiration to my practice. I am also grateful to Gemma Griffith for stepping in as my Bangor link, and to Robert Jones for his encouragement and wise advice at my reviews.

Thank you to the States of Jersey for supporting this research. Special thanks to Chris Dunne and Steve McVay for their support during this process. Thank you also to Doc Snook and CarolAnn Romeril for their support, data collection and skilled work in the field of PBS in Jersey. Thank you to Martin McMahon for his work on coding medication and encouragement.

I am grateful to my parents for shaping my work ethic and this thesis is for them. I could not have done it without the support of my wife and children, so Andrea thank you! Andrea's values and commitment to the people she supports, as a learning disability nurse, further inspires my daily practice and motivated my research efforts.

And finally, thank you to the people of Jersey who took part in this research. The work does not stop here! I will ensure that the research informs practice in Jersey to ensure people with developmental disabilities receive the best support possible. Only then will this research be worth the effort.

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SUMMARY

Positive Behavioural Support (PBS) is a multicomponent framework designed to address the multiple factors that influence an individual's behaviour, with a focus on improving quality of life (Kincaid *et al.* 2002). PBS, in the UK, has largely been implemented by peripatetic community teams, in developmental disability (DD) services. High prevalence of challenging behaviour in individuals with DD (Jones *et al*. 2008) is a result of the interaction between vulnerability, environmental and impact factors (Hastings *et al*. 2013). This thesis will attempt to expand existing knowledge on all three of these aspects in relation to PBS as an intervention model.

The thesis begins by presenting a total population study regarding the prevalence of challenging behaviour (chapter 2). This study investigates the associated correlates of challenging behaviour, and is the first study to consider the cumulative association of these correlates and propose ways to measure cumulative risk. Chapter 3 considers an impact of challenging behaviour – the high incidence of psychotropic medication use - and explores prescribing patterns associated with various topographies of challenging behaviour. In chapter 4, population data from the Behaviour Problems Inventory – Short Form (Rojahn *et al*. 2012) are used to estimate norms, clinically significant change and reliable change statistics. This chapter also provides guidance through examples on how this information can be used in research and clinical practice to enable practitioners to evaluate behaviour change in a more robust manner. Chapter 5 is an evaluation of outcome data from a peripatetic PBS service and, for the first time in research, considers statistically meaningful behaviour change (utilising evidence from Chapter 4), quality of life and social validity impacts. Finally, in chapter 6, findings from the four empirical studies are discussed in relation to theoretical implications. Implications for further research and practice in the field of PBS are proposed in chapter 6.

CHAPTER 1

Positive Behavioural Support: An introduction to the literature and background to the thesis.

Positive Behavioural Support (PBS) is a multi-component framework that aims to improve quality of life in individuals with developmental disabilities (DD) and reduce levels of challenging behaviour (Carr *et al.* 1999; Horner, 2000; Fox & Emerson, 2010; La Vigna & Willis, 2012; Toogood *et al*. 2015; Kincaid *et al.* 2016). PBS combines the behavioural technology of Applied Behaviour Analysis [ABA] (Cooper, Heron & Heward, 2007), with the value base of person centred approaches (O Brien & O'Brien, 2002), social role valorisation and normalisation theory (Wolfensberger, 1983), with stakeholder participation a key component (Carr *et al.* 2002; Gore *et al*. 2013). PBS is often viewed as an 'application' of ABA in support of people who may display challenging behaviour (LaVigna & Willis, 2012), a 'model' of delivering ABA services (Wacker & Berg, 2002) or an intervention 'package' (Smith, 2013). Whilst the components of PBS are not new, the way they are integrated into an intervention package is different (Carr *et al.* 2002). Baer, Wolf and Risley (1968) describe the technological feature of ABA – its intervention techniques are precise, detailed and replicable. ABA procedures are well-defined and analysed, often in single subject designs (Smith, 2013). Solving behaviour problems in natural settings requires multiple intervention procedures, and the combination of these into a 'package' is what defines PBS (Smith, 2013). It is thus important researchers evaluate the outcomes of PBS as a 'package' in group studies (Smith, 2013). There is an emerging evidence base from meta-analytic reviews (Carr *et al*. 1999; La Vigna & Willis, 2012) and recent research studies (McLean *et al.* 2007; Hassiotis *et al.* 2009; McKenzie & Patterson, 2010; Allen *et al.* 2011) that PBS is effective at reducing levels of challenging behaviour. Whilst initial results are encouraging, early research has been limited by methodological weaknesses and a consistent failure to assess change in quality of life and explore the social validity impact of interventions (Carr *et al.* 2002; Kincaid *et al.* 2003; McLean *et al.* 2005).

Further research to address these deficiencies is timely given the renewed interest in PBS in the UK (Toogood *et al.* 2015, 2016). PBS models of practice were recommended in the first Mansell Report (Department of Health, 1993) to serve more complex individuals within their local communities. A number of teams developed, yet individuals with DD continued to be exposed to the aversive, punishment procedures dominating practice (Allen *et al.* 2011), whilst being excluded from community settings due to challenging behaviour (Department of Health, 2007). Interest in the peripatetic team model has increased as an alternative to these much-criticised models of assessment and treatment units implicated in more recent abuse scandals (e.g. Winterbourne View facility). PBS has been suggested as a key approach to improve practice for people with challenging behaviour (Ball *et al.* 2004; British Psychological Society, 2004; RCP/BPS/RCSLT, 2007; Royal College Psychiatrists 2016). It has further featured in local and national government policy (Department of Health 2012a, b, 2013, 2014; Local Government Association and NHS England, 2014; Transforming Care and Commissioning Steering Group, 2014) and national clinical guidelines (NICE, 2015, 2017; Skills for Care, 2014). There has also been progress in terms of defining PBS and documenting the multi-elements that, featured together, make up the PBS Framework (Gore *et al.* 2013).

The aim of this thesis was to advance PBS research literature at a time of renewed national interest in the PBS model, with a strong focus on methodological advances in the four studies described in chapters two to five. There was also a desire to explore issues relevant to the States of Jersey and the community it serves, and for the research to have a strong applied emphasis.

Challenging behaviour and developmental disability

The first three research studies described in chapters two to four involved adults (aged ≥ 18 years of age) with Intellectual Disability (ID). Data collected as part of the total population study, described in chapter two, formed the basis of the studies reported in chapters three and four. ID is defined by a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence IQ≤70), with a reduced ability to cope independently (impaired social functioning) which started before adulthood, and has a lasting effect on development (World Health Organisation, 2010). The final research study presented in chapter five, which described an evaluation of outcome data from a peripatetic PBS service in Jersey, involved individuals of all ages with Developmental Disorder (DD). DD is an umbrella term covering disorders such as ID, as well as pervasive developmental disorders including autism. Autism is a life-long neurodevelopmental disorder characterised by difficulties with social communication, interaction, repetitive behaviours and interests (Lai, Lombardo & Baron-Cohen, 2014). It is estimated that the prevalence of ID is 2% (BPS, 2011) and in England in 2015 there were 1,087,100 people with ID including 930,400 adults (Public Health England, 2015). It is further estimated that 1 percent of the population in the UK have autism (Baird *et al.* 2006) and approximately half of children with autism also have an ID (Totsika *et al.* 2011), with a UK population estimate of over 700,000 people with autism (NHS information Centre, 2012).

Challenging behaviour is very common in individuals with developmental disabilities. Over the past 30 years, there have been a number of studies concerning the nature, extent and impact of challenging behaviours shown by individuals with ID and/or autism (McClintock, Hall, & Oliver, 2003). Studies show that individuals with ID are three to five times more at risk of displaying challenging behaviour than the population average (Poppes, van der Putten, & Vlaskamp, 2010). Similarly, individuals with autism are estimated to be four times more at risk of displaying challenging behaviour compared to non-autistic adults (McCarthy *et al*. 2010).

In this thesis I use the term ‘Challenging Behaviour’ consistent with other academic studies. This term was introduced to replace a variety of labels which previously identified behaviour as a problem ‘within’ and ‘by’ the individual. It is important to acknowledge that the term ‘challenging behaviour’ has also been used inappropriately as a diagnostic label in recent years. The term ‘challenging behaviour’ is used in this thesis with the intention to place the cause within the environments it occurs, with solutions arising from changes within this social context and by addressing aspects of the framework model which will be described later (Hastings *et al*. 2013). This constructionist view places the emphasis on services and carers to better understand the causes of challenging behaviour and find positive solutions (Allen *et al.* 2013). PBS as a framework model is a broad approach that can address multiple contributing factors and processes involved in the development of challenging behaviour (Hastings *et al*. 2013).

Challenging behaviour is defined socially in two ways. Firstly, behaviour may be considered challenging when it occurs outside of cultural or societal norms (Emerson & Einfeld, 2011). Secondly, it may be considered challenging when it occurs with such frequency, intensity or duration that it has social consequences. These consequences are defined by risk of harm to the individual or others, environmental damage, or social exclusion (Emerson & Einfeld, 2011). Consequences can also be defined in terms of impact to quality of life, or where they lead to aversive or restrictive practices (RCP, BPS, RCSLT, 2007). Many people who present challenging behaviour in the UK have been excluded from their local communities, and often placed out of area (DoH, 2007). There are not enough skilled services to meet their needs and address risk issues in their local communities (DoH, 2007).

Understanding the prevalence of challenging behaviour in individuals with ID is essential if services are to be developed to meet needs. Research on the prevalence of challenging behaviour in individuals with ID to date has been restricted by the greater focus on specific clinical populations in specific clinical settings (Emerson *et al*. 2001a). The most robust methodology to estimate prevalence of challenging behaviour is to sample at the population level. Reported prevalence shows considerable variation between 4-22% in previous total population studies (Holden & Gitlesen, 2006; Jones *et al.* 2008), to as high as 50-80% in studies looking at specific settings, subpopulations or behaviours (Bouras & Drummond, 1992; Poppes *et al.* 2010). Some variation can be explained by differences in study designs and methodologies (for summaries see: Jones *et al*. 2008; Cooper *et al.* 2009b). There remains no consistent, conceptual, consensual or operational definition of challenging behaviour used in research studies. Challenging behaviour has been a particularly difficult variable to define consistently and establish validity on (Kiernan & Moss, 1990). Previous research has been limited also by the lack of psychometrically evaluated assessment and classification tools developed specifically for adults with ID to explore challenging behaviour (Jones *et al*. 2008). A number of studies have been restricted in their sampling methods by extracting data from sources not designed to hold accurate data, such as clinicians' notes (e.g. Borthwick-Duffy, 1994; Jacobsen, 1982; Sheehan *et al.* 2015), or by postal surveys utilising numerous informants who may lack precise information regarding the occurrence of challenging behaviour (e.g. Crocker *et al*. 2006). In a previous meta-analysis exploring risk factors in challenging behaviour studies, only 22 of the 86 studies considered were found to contain enough information to be included; fewer than half of these used a questionnaire type instrument and very few any psychometrically evaluated tools (McLintock *et al*. 2003). These issues will be addressed in the total population study on the prevalence of challenging behaviour and exploration of cumulative risk indices, described in chapter two.

A framework for understanding challenging behaviour

In developing a causal model of why challenging behaviour occurs it is important to understand the social context (Hastings *et al.* 2013). Figure 1 describes a framework for understanding challenging behaviour (Hastings *et al*. 2013). This framework indicates that challenging behaviour is the product of the interaction between biological, developmental and environmental factors (Allen *et al*. 2013).

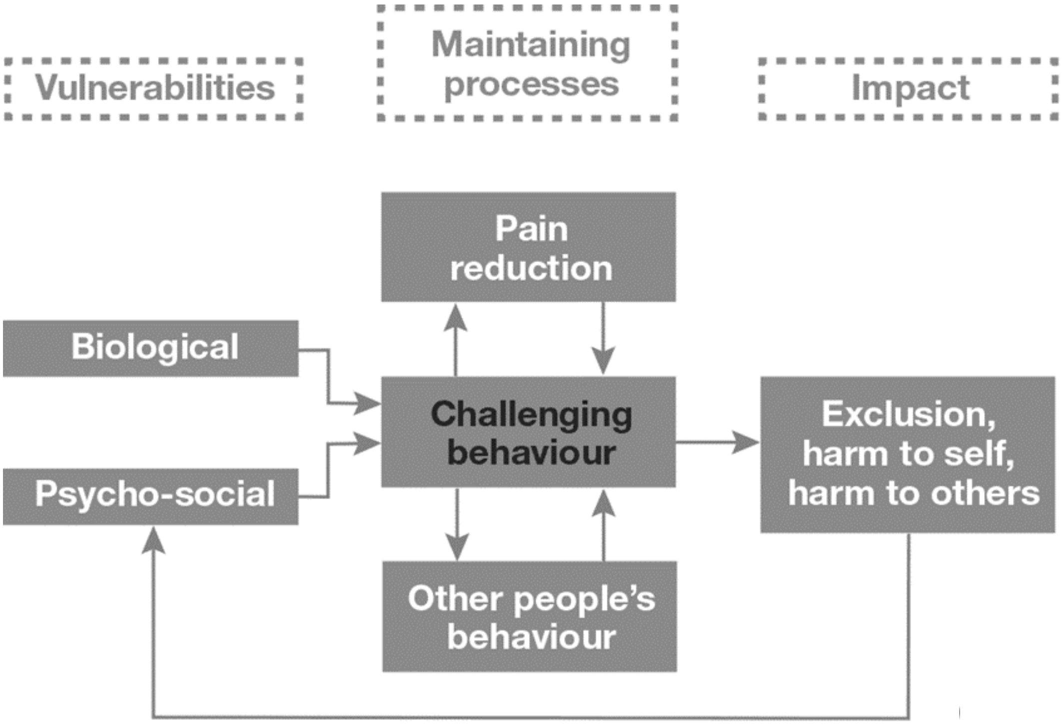

Figure 1. A Framework for understanding why challenging behaviour occurs (Hastings et al. 2013).

Vulnerabilities of challenging behaviour

This model initially highlights the biological and psycho-social vulnerabilities, identified in research literature, which appear related to higher levels of challenging behaviour for people with DD. Biological vulnerabilities include sensory causes, physical health issues, and genetics. Some genetic syndromes associated with ID have an increased risk of challenging behaviour (e.g. self-injurious behaviour in Cornelia de Lange Syndrome; Hyman *et al.* 2002).

Psycho-social vulnerabilities include negative life events, lack of communication skills, impoverished social networks, lack of meaningful activity, and psychiatric or mood problems (Hastings *et al*. 2013). Some vulnerabilities appear to have been consistently identified in studies associated with higher levels of challenging behaviour, such as lack of communication skills (Emerson & Bromley, 1995; Emerson *et al.* 2001a; Holden & Gitlesen, 2006; Jones *et al.* 2008). Other vulnerabilities, such as psychiatric problems, have been reported to be associated with higher levels of challenging behaviour in some studies (e.g. Lowe *et al*. 2007; Lundqvist, 2013), but not consistently in others (e.g. Jones *et al*. 2008). There is little robust literature to compare factors associated with higher levels of challenging behaviour (Jones *et al.* 2008). Previous studies have been criticised for a failure to identify the differential importance of associated factors in their analysis or for conducting this analysis only on specific populations with challenging behaviour and not total population groups (Lundqvist, 2013; Cooper *et al*. 2009). The study described in chapter two will address these issues and explore factors associated with challenging behaviour in a total population of adults with ID in Jersey. For the first time in research literature, the potential for exploring the cumulative impact of these associated factors will be explored. This will inform future PBS practice that looks to address challenging behaviour by developing preventative strategies related to associated vulnerabilities.

Maintaining processes and challenging behaviour

The above framework (Figure 1) also indicates that challenging behaviour is maintained by the social consequences that follow and are related to the responses of others (Hastings *et al.* 2013; Gore *et al.* 2013). In this sense, challenging behaviour is functional as it serves an important purpose for the individual (Iwata *et al.* 1994). Functions of behaviour can include stimulation, attention, tangible and escape from demands (Carr *et al*. 1977). Pain reduction has recently been added to this list (Hastings *et al.* 2013). To understand challenging behaviour, it is necessary to understand the circumstances that occur before and what happens after the behaviour (Gore *et al.* 2013). People with DD have historically experienced impoverished social contact, low levels of engagement and aversive interactions (Hastings *et al*. 2013). Challenging behaviour can often be a very effective means of addressing these issues. In order to understand the maintaining processes, a functional behavioural assessment of the social and physical environment and context in which the challenging behaviour occurs is needed (Iwata *et al*. 1982). This explains how the existing behaviour helps the individual manage or exert control over their environment which informs the development of a more effective and person-centred intervention plan (Iwata *et al*. 1982; Sprague & Horner, 1995; O Neil *et al.* 1997; Didden *et al.* 1997; McGill 2013; O Neil *et al.* 2015). Research indicates that interventions for challenging behaviour based on prior functional assessment have greater success rates (Carr *et al.* 1999). The research described in chapter five will consider this area by exploring outcome data from a PBS team in Jersey, where interventions are designed based on prior functional behavioural assessments.

The impact of challenging behaviour

For individuals with DD, challenging behaviour can lead to negative personal outcomes and diminished quality of life (Emerson *et al*. 2001a). It can result in poor integration, exclusion from services, limited friendships, interference with learning and development, and adverse psychological implications such as low self-esteem and increased anxiety (Cooper *et al*. 2009b; Holden & Gitlesen, 2006). Studies have shown that challenging behaviour may lead to long-term inpatient care with an increased risk of physical harm and abuse (Emerson *et al*. 2001a; Glover & Olson, 2012). It can lead to an increased reliance on restrictive practices such as seclusion or restraint (Matson *et al*. 2000; Matson & Nebel-Schwalm, 2007; RCP, 2007). Challenging behaviour can result in negative consequences for carers as well, including risks of assault and stressful emotional reactions (Cooper *et al.* 2009b; Hastings & Brown, 2002). These responses can have a cyclical impact as they further affect the person’s psycho-social vulnerabilities (Hastings *et al.* 2013).

Research has indicated that adults with ID and challenging behaviour are prescribed more psychotropic medications than those without challenging behaviour (Fleming *et al*. 1996; Holden & Gitlesen, 2003; Aman & Ramadan, 2007; Crossley & Withers, 2009; Doan *et al*. 2013; Scheifes *et al*. 2015). There are significant side effects of these medications with weight gain, somnolence, metabolic syndromes and behavioural impacts being reported (Deb & Unwin 2007; Maher *et al*. 2011; Deb *et al.* 2014; Wilner, 2014; Scheifes *et al.* 2015; Sheehan *et al.* 2017). These impact issues will be investigated in the study on the prevalence of psychotropic medication and associated factors in adults with ID in Jersey, described in chapter three.

Providing support packages involving challenging behaviour can be expensive and demanding for service providers (Cooper *et al*. 2009b). The impact of challenging behaviour is significant in terms of costs (Knapp *et al*. 2005; Department of Health, 2012). Annual service costs in the UK of £89,335 - £358,415 have been identified for adults with challenging behaviour (McGill & Poynter, 2012). One study revealed that of the £17m NHS trust budget to serve a population of between 3000-6000 people with ID, £11m was spent on just 107 people placed out of area for challenging behaviour treatment (Allen *et al.* 2007). Services have been criticised for the overuse of out-of-area placements, institutional care and restrictive practices (Allen *et al*. 2007; Bubb, 2014; British Psychological Society, 2011; Challenging Behaviour Foundation, 2014). Studies reveal that a large number of individuals presenting challenging behaviour are placed out of area (33%: DOH 2004; 29.2% Jaydeokar & Piachaud, 2004), where care can be of variable quality and impact on community integration (SCIE 2012; Baron *et al.* 2011; Chinn *et al*. 2011). When individuals are placed out-of-area little effort appears to be made to increase competence or address deficiencies in the home environment, which acts as a barrier to discharge (McLean *et al.* 2005). In the Allen *et al*. (2007) study, of people with ID placed out of area for challenging behaviour treatment, 37% had no behaviour support plan and 50% no access to psychology. Any potential behaviour change that could occur in the environmental context of a specific treatment unit may not be maintained once the person returns to their local community (McLean *et al.* 2005). Such services also experience a high level of staff turnover (Felce *et al*. 1993; Hatton *et al*. 2001), higher rates of injury to service users, lower rates of community activity, higher rates of psychotropic medication and higher costs (Robertson *et al.* 2002). Recent guidance has reiterated recommendations from the first Mansell Report (DoH, 1993) for disability services to develop competencies to support people in their local community (NHS England, Local Government Association and Association of Directors of Adult Social Services, 2015). The expectation is that people are supported to live in their local community and barriers to this are overcome (Saville *et al*. 2016). The absence of such support systems for people with challenging behaviour has been shown to be a determinant of placement breakdown and out-of-area placement (Beadle-Brown *et al*. 2006; Goodman *et al*. 2006; Phillips & Rose 2010).

What is Positive Behavioural Support?

PBS emerged in the 1980s as an alternative to behaviour modification practices that featured contingency management often utilising aversive punishment procedures (Kincaid *et al.* 2016). PBS is a service delivery model that utilised the technology of Applied Behaviour Analysis (ABA) with an emphasis on a values led and person-centred framework (Allen *et al.* 2011). Where behaviour analysis is the philosophy and science, ABA is the application of that science to issues of social significance. It is often suggested that PBS is ABA plus values, but the values of those who work with people with ID are also long accepted values of behaviour analysis, including values such as respect, person-centred planning, self-determination, normalisation and stakeholder participation (Johnston *et al.* 2006). In fact, in Beyond Freedom and Dignity (1971) Skinner saw punishment as the logical consequence of an unscientific analysis of human behaviour and against the tradition of freedom and dignity. Skinner (1971) described the operant nature of behaviour, and argued against punishment which he saw to be ineffective in controlling behaviour. PBS, as a model, avoids the use of aversive sanction based approaches. Skinner proposed a technology of behaviour analysis to solve pressing human issues. Early proponents of behaviour analysis described the applied, socially important nature of the application of behaviour analysis (Baer, Wolf & Risley, 1968). The application of behaviour analysis additionally required effective treatment, for results to have sufficient change to be of value to the individuals (Baer, Wolf & Risley, 1968), the social validity aim of PBS.

PBS as a framework model (Gore *et al.* 2013) is defined by the use of a functional assessment for challenging behaviour; altering deficient environmental conditions; altering deficient behavioural repertoires; and achieving lifestyle change and improved quality of life through multi-component intervention plans whilst reducing levels of challenging behaviour (Donnellan *et al*. 1985; Mclean *et al*. 2007). Targeting a reduction in the ‘impact’ issues described above is a key aim of PBS, such as reducing restrictive practices and promoting community inclusion. The PBS model can respond to all aspects of the framework model described in Figure 1 (Hastings *et al*. 2013), addressing biological and psycho-social vulnerabilities (e.g. teaching communication skills and improving engagement levels); understanding maintaining processes through functional assessments of behaviour and utilising the behaviour change technology of ABA; and addressing impact factors through quality of life, values led and stakeholder informed interventions. In a recent review of the definition Kincaid *et al.* (2016. p4) define PBS as:

> “an approach to behavior support that includes an ongoing process of research-based assessment, intervention, and data-based decision making focused on building social and other functional competencies, creating supportive contexts, and preventing the occurrence of problem behaviours. PBS relies on strategies that are respectful of a person’s dignity and overall well-being and that are drawn primarily from behavioural, educational, and social sciences, although other evidence-based procedures may be incorporated. PBS may be applied within a multi-tiered framework at the level of the individual and at the level of larger systems (e.g., families, classrooms, schools, social service programs, and facilities)”.

Further detail on the assessment and intervention process which characterises PBS is provided in chapter five.

Donnellan *et al’s*. (1985) study first described the positive impact of a specialist team on challenging behaviour in a natural setting. Since then, two reviews (Carr *et al*. 1999; La Vigna & Willis, 2012) and several small studies (e.g. McLean *et al.* 2007; Hassiotis *et al.* 2009; McKenzie & Patterson, 2010; Allen *et al.* 2011; Davidson *et al.* 2015) have presented encouraging results regarding reductions in challenging behaviour following peripatetic PBS service input in community settings. There is considerably less evidence on the impact on quality of life and other social validity outcomes that PBS aims to achieve (Mclean *et al.* 2005).

PBS Teams

In the UK PBS developed within specialised peripatetic teams for people with DD. In the USA, and other countries, it has also been implemented at a system level, as in school-wide PBS (Kincaid *et al.* 2016). Specialist PBS teams are designed to serve a small number of individuals whose behaviour or referral environment is complex, and support mainstream services to develop competencies to support people in their local communities (Toogood *et al*. 2015). The first peripatetic challenging behaviour team was launched in the UK thirty years ago (Emerson *et al*. 1987). Many of these early teams published descriptions of their functions, the practice of a number was similar to what is identified as PBS today, and some provided some encouraging preliminary outcome data (McBrien, 1994; Toogood *et al*. 1994ab; Allen & Lowe, 1995; Lowe *et al*. 1996; Forrest *et al.* 1996; Emerson *et al*. 1996; McGill, 2000). In 1996, 65 teams were identified across England and Wales (Emerson *et al*. 1996). Whilst many reported favourable outcomes, it was considered that results based on self-assessment of service efficacy should be treated with some caution (Davison *et al*. 2015), and additional studies which scrutinised impact in more detail raised questions such as discovering that, in one investigation, cases were closed for factors other than significant improvements in challenging behaviour (Emerson *et al.* 1996). Early research concluded that despite the growing investment into such services, and the view that they were models of good practice, there was limited research evidence for their effectiveness (Lowe *et al*. 1996; Hassiotis *et al*. 2009; McKenzie, 2011; Inchley-Mort *et al*. 2014). Existing research has been criticised for focusing on single case studies; children/young people; more disabled individuals; a limited range of problems, and on delivery by specialists in institutions (Allen *et al.* 2011). Other criticisms are that PBS is not effective for severe challenging behaviour (Foxx, 2005) and has not demonstrated evidence of socially significant change in quality of life and adaptive behaviours (Carr *et al*. 1999).

It also appeared that there was a period of disinvestment (Toogood *et al*. 2015) and the number of teams in the UK decreased 30% from 65 in 1996 (Emerson *et al.* 1996), to 46 in 2015 (Davison *et al.* 2015). It has been suggested that where teams exist they have large caseloads, which impacts on the receipt of prompt service for those requiring support (Emerson *et al*. 1996; Davidson *et al.* 2015). Further research to explore the effectiveness of peripatetic PBS teams is required to inform applied development and potential investment (Allen *et al.* 2011), especially given the recent upsurge in interest and growing demand for such services (Toogood *et al*. 2015). Chapter five in this thesis will address these issues, and some of the limitations of earlier research, by exploring outcome data from a PBS service in Jersey.

The PBS service in Jersey.

A specialist challenging behaviour team was created in Jersey in 1999 and was originally titled the Intensive Support Team. The team was created to support the move of adults with ID and challenging behaviour to community homes from the long stay hospital which closed in 2004. In 2003, the service began to take referrals from individuals of all ages and from people diagnosed with autism. The team also supported the return of several adults with DD to Jersey who had previously been placed in the UK for behavioural treatment, with every adult returning to the island by 2005. In 2005, the service changed its name to the Positive Behavioural Support team to reflect the alignment with the PBS model. The PBS team currently features a Senior Behaviour Advisor (my role), a Behaviour Advisor and a Behaviour Advisor Assistant. The prime focus is case work delivering PBS interventions for individuals of all ages with a diagnosis of ID and/or autism and who are presenting challenging behaviour. The team also deliver an extensive training programme for care staff. The PBS team sits with the community multi-disciplinary team that features social workers, nurses, occupational therapists, physiotherapists, psychologists and psychiatrists. All the research studies presented in this thesis were designed so that the results would have applied use in the design and provision of services in Jersey.

Jersey is a small island of 118 square kilometres, 22 kilometres from the coast of Normandy, France, and 161 kilometres south of England. It is the largest of the group of Channel Islands. Jersey is a self-governing parliamentary democracy with separate judicial, financial and legal systems from the United Kingdom. The cultural influence is predominantly British, with English spoken and the British pound the currency. The population of Jersey during the data collection process was 102,700 (States of Jersey, 2015). Given suggested prevalence rates of ID and Autism (ID 2%, BPS 2011; Autism 1.0%, Baird *et al*. 2006), this would suggest a potential population of 2054 individuals with ID and 1027 with Autism (some of these will also have an ID).

Measuring Challenging Behaviour

Previous research has been limited by the lack of psychometrically evaluated tools to assess and classify challenging behaviour (Jones *et al*. 2008). Measuring challenging behaviour was a key aspect in the methodology of all studies described in this thesis, so identifying an appropriate measure was important. Researchers initially explored a number of different behaviour rating scales to measure challenging behaviour. Measures explored included the Aberrant Behavior Checklist – ABC (Aman & Singh, 1986); the Developmental Behavior Checklist (Einfield & Tonge, 2002); the Behaviour Problems Inventory – Short Form (Rojahn *et al.* 2012); the Challenging Behaviour Interview (Oliver *et al.* 2003); the Adult

Scale of Hostility and Aggression: Reactive / Proactive (Matlock & Aman, 2011); the Children's scale of Hostility and Aggression: Reactive / Proactive (Farmer & Aman, 2009); the Adult Behaviour Checklist (Achenbach & Rescorla, 2003); the Challenging Behaviour Scale (Moniz-Cook, *et al*. 2001); the Checklist of Challenging Behaviour (Harris, Humphreys & Thomson,1994); the Overt Aggression Scale (Yudofski, *et al.* 1986); the Nisonger Child Behaviour Rating Form (Aman *et al*. 1996); and the Staff Observation Aggression Scale (Nijman *et al.* 1999). All tools were evaluated against the following criteria: The rating scale must be suitable for Intellectual Disabilities / autism; the rating scale must be suitable for children and adult studies; the rating scale must be 'broad band' and cover appropriate topographies of behaviour; the rating scale must have good psychometric properties and have been previously utilised in research studies; the rating scale must be 'user friendly' and be suitable for larger studies on population groups (chapters two, three and four); the rating scale must be appropriate to assess outcome measures for a PBS service study (chapter five); the rating scale must be low-cost. The Behaviour Problems Inventory – Short Form [BPI-S] (Rojahnn *et al*. 2012a, b) was deemed the best fit and was utilised in all research studies described in this thesis (Appendix I).

Structure of the thesis

The thesis consists of a further five chapters; four research studies and a discussion chapter. Versions of each of the four research studies have been published or submitted for publication, so each chapter is written as a stand-alone piece of work. The aim of the thesis was to explore all aspects of the framework model for understanding the causes of challenging behaviour to inform Positive Behavioural Support approaches. Each of the empirical studies focuses on an aspect of the causal framework, with the final study exploring the impact of PBS in a community setting as an intervention for individuals with DD who present challenging behaviour.

Chapter two focuses on 'vulnerabilities' from the framework model. Research is presented on the prevalence and correlates of challenging behaviour in the total population of adults with ID in Jersey. Having an accurate understanding of prevalence is important for the development of services. Findings on correlates may highlight populations at risk of developing challenging behaviour. The use of relative risk statistics in this study uniquely assists identification of the correlates PBS services should prioritise for intervention. For the first time in ID research, I explore the cumulative impact of correlates, and propose ways of building and testing exploratory cumulative risk indices (CRIs). The aim of this approach was to identify a method of developing a CRI that clinical services will be able to use in the future (following longitudinal replication to establish its predictive validity) to predict the risk of presenting challenging behaviours and design interventions targeting multiple risk factors.

The third chapter explores a potential ‘impact’ of challenging behaviour not currently listed in the framework model (Hastings *et al*. 2013) – higher prevalence of psychotropic medication use. Recent research has indicated that challenging behaviour, presented by individuals with ID, is associated with an increased use of psychotropic medication (Sheehan *et al*. 2015). Prescribing of psychotropic medication appears common despite the lack of research evidence for its effectiveness in addressing challenging behaviour (Emerson & Baines, 2010; Tsiouris 2010; Paton *et al*. 2011; Wilner, 2014). As a result, there is a national effort to reduce levels of prescribing (e.g. STOMP: Stopping the over-medication of people with a learning disability, autism or both, https://www.vodg.org.uk/campaigns/stompcampaign/). Chapter 3 examines this crucial and current issue by exploring the prevalence of psychotropic medication use in adults with ID in Jersey and examining the relationship between prescribing and challenging behaviour. Few studies have examined prevalence of psychotropic medication in total population samples identified from multiple routes. There are limitations in existing studies, with a lack of standardised medication classification tools utilised, and varying definitions of challenging behaviour used. In this study, psychotropic medication use was estimated from a robust total population sample in Jersey and coded using an internationally recognised system (the World Health Organisation Anatomic Therapeutic Classification Scheme - WHO, 2014; WHOCC – ATC/DDD, 2014). Associations with specific topographies of challenging behaviour were measured and classified, for the first time in research, utilising existing data gathered in the population study described in chapter 2 from the BPI-S (Rojahn *et al.* 2012).

Chapter four is concerned with the development of the BPI-S rating tool (Appendix I) to extend its use in research and clinical practice. Data gathered from the 265 participants in the total population study (chapter 2) was utilised in this research. This was intended to be a very practical chapter with case examples provided to support services and practitioners to utilise the useful statistics developed on population norms, statistically significant and clinically significant change scores. The aim was to develop this psychometrically evaluated tool to measure behaviour change in research, or in clinical practice, where professionals are tasked with reducing levels of challenging behaviour. Following the development of the BPI-S in this study, a number of applied benefits of using the tool, for Positive Behavioural Support services, are described in chapter 6.

The fifth chapter in this thesis examines outcome data from the PBS service in Jersey over the course of four years, which represents one of the largest sample sizes seen in such studies. The BPI-S data established in chapter four was critical to evaluate whether service input led to clinically significant and reliable behaviour change in this study. With a key aspect of PBS team input being the completion of functional behaviour assessments (Gore *et al.* 2013) this study explores outcome data when 'maintaining processes' are identified, and a PBS multi-element intervention plan is implemented with collaborative stakeholder participation. The study also explores the impact of PBS on quality of life and social validity, an area lacking in previous research.

The final chapter, six, is a discussion of the studies described in the thesis. It draws together findings from the studies and summarises the key findings. Implications for the field of Positive Behavioural Support are outlined and recommendations for further research and applied practice are suggested.

CHAPTER 2

Challenging behaviours in adults with an intellectual disability: a total population study and exploration of risk indices.[1]

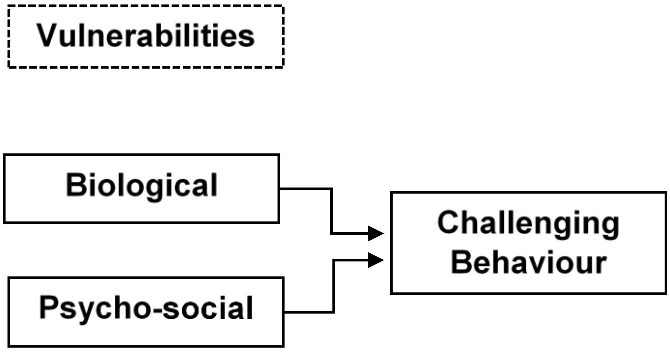

Figure 1. Vulnerabilities: Framework for understanding why challenging behaviour occurs (Hastings et al. 2013).

The focus of chapter two is on the first section of the framework for understanding why challenging behaviour occurs (Figure 1) - vulnerabilities. The chapter comprises a total population study into the prevalence of challenging behaviour in adults with intellectual disability in Jersey. The chapter describes personal and demographic characteristics that are associated with various topographies of challenging behaviour, to inform knowledge of the vulnerabilities associated with challenging behaviour. The chapter also extends research by considering the cumulative impact of associated factors and proposes five different methods of developing cumulative risk indices. Challenging behaviour data collected in this chapter also informed research studies described in chapters 3 and 4.

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[1] A version of this chapter was published as: Bowring D. L., Totsika V., Hastings R. P., Toogood S. & Griffiths G. M. (2017) Challenging behaviours in adults with an intellectual disability: a total population study and exploration of risk indices. *British Journal of Clinical Psychology,* vol 56, no. 1, 16-32.

Abstract

Background. Considerable variation has been reported in the prevalence and correlates of challenging behaviour in adults with intellectual disabilities. To provide a robust estimate of prevalence, we identified the entire administrative population of adults with ID in a defined geographical area and used a behaviour assessment tool with good psychometric properties.

Methods. Data from 265 adults who were known to services were collected using a demographic survey tool and the Behavior Problems Inventory – Short Form. The prevalence of self-injurious, aggressive/destructive, stereotyped, and overall challenging behaviour was evaluated. We explored the potential of developing Cumulative Risk Indices (CRI) to inform longitudinal research and clinical practice.

Results. The prevalence of overall challenging behaviour was 18.1% (95% CI: 13.94%-23.19%). The prevalence of self-injurious behaviour was 7.5% (95% CI: 4.94%-11.37%), aggressive and destructive behaviour 8.3% (95% CI: 5.54%-12.25%), and stereotyped behaviour 10.9% (95% CI: 7.73%-15.27%). Communication problems and severity of ID were consistently associated with higher risk of challenging behaviours. CRIs were significantly associated with challenging behaviours and the five methods of CRI development produced similar results.

Conclusions. Findings suggest a multi-element response to challenging behaviour is likely to be required that includes interventions for communication and daytime activity. Exploratory analyses of CRIs suggested these show promise as simple ways to capture cumulative risk in this population. Subject to longitudinal replication, such a tool may be especially useful in clinical practice to identify adults who are priority for interventions and predict future demand on services.

Keywords Intellectual disability, challenging behaviour, cumulative risk, relative risk, population sample

Introduction

The most robust methodology for estimating prevalence of challenging behaviour in adults with intellectual disabilities (ID) is to sample at a population level. However, the prevalence of challenging behaviour reported in administratively defined population studies shows considerable variation: from 4% in Holden & Gitlesen's (2006) study in Norway to 22% in Jones *et al's* (2008) study in Scotland, for example. Inconsistencies are also apparent in the correlates of challenging behaviour. The presence of autism, for example, has been identified in some studies to be associated with higher levels of challenging behaviour (Lundqvist, 2013), but not in others (Jones *et al*. 2008). Variability in prevalence and correlates may be a function of differences in sampling methodology and in the definitions of challenging behaviour (Emerson *et al.* 2001a). This variability is confusing and may impede accurate service planning and the development of effective interventions (Lowe *et al.* 2007; Jones *et al*. 2008; Lundqvist, 2013).

Variability is likely to emerge in the estimation of prevalence when definitions of challenging behaviour differ (Cooper *et al.* 2009a). Kiernan and Qureshi (1993) attempted to overcome this problem by differentiating between challenging behaviour that is 'more' or 'less' demanding. They defined challenging behaviour as 'more demanding' when it occurred daily, restricted engagement, required physical intervention, or resulted in a major injury. Using this definition, with mixed age groups, has yielded estimates of 'more demanding' challenging behaviour of 3.8% (Holden & Gitlesen, 2006), 5.7% (Kiernan & Qureshi, 1993), 7.8% (Emerson & Bromley, 1995), 5-10% (Emerson *et al*. 2001a), and 10% (Lowe *et al*. 2007). Including 'less demanding' challenging behaviour (aggression, destruction, self-injury or other problem behaviour, which did not meet the above criteria) increased prevalence estimates to 10-15% (Emerson *et al*. 2001a) and 11.1% (Holden & Gitlesen, 2006). It is important to note that there remains no agreed consensual, conceptual or operational definition of challenging behaviour.

Two more recent population-based studies report challenging behaviour prevalence in adults rather than mixed age population samples using classification tools designed for adults with ID and challenging behaviour. Jones and colleagues (2008) included adults aged 16-years and older and defined challenging behaviour using psychiatrists' assessment and diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation (DC-LD) (Royal College of Psychiatrists, 2001). These adults were assessed by psychiatrists using a purpose-designed measure based on DC-LD criteria and other assessment tools including the Psychiatric Present State for Adults with Learning Disabilities (PPS-LD) (Cooper, 1997), an autism assessment derived from DCR-ICD 10 (WHO, 1993), and the Vineland Adaptive Behavior Scales (Sparrow, Balla & Cicchetti, 1984). Psychiatric assessment produced an overall estimate for challenging behaviour of 22.5%, compared with 18.7% using the DC-LD criteria. In the other population-based study, Lundqvist (2013) used the Behavior Problems Inventory (Rojahn *et al*. 2001) to identify challenging behaviour in adults aged over 18-years in Sweden. Only behaviour rated on the BPI as having a severe impact (on a 4 point scale ranging from 0=never/no problem, to 3=severe) was defined as challenging. The overall prevalence of challenging behaviour was estimated at 18.7%. These two studies indicate that prevalence rates may be higher than the earlier population studies above that defined challenging behaviour in terms of ‘more’ or ‘less demanding’.

In total population studies, increased severity of ID and the presence of communication difficulties have typically been found to be associated with more frequent or severe challenging behaviour (Emerson & Bromley, 1995; Emerson *et al*. 2001a; Holden & Gitlesen, 2006; Jones *et al*. 2008). There is more conflicting evidence regarding other potential correlates. Some studies found men were at greater risk of presenting challenging behaviour than women (Kiernan & Qureshi, 1993; Emerson *et al*. 2001a). Other studies, however, found women were at greater risk than men (Jones *et al*. 2008), or that there is no association between gender and challenging behaviour (Holden & Gitlesen, 2006). Associations have been reported between challenging behaviour and psychiatric diagnoses (Lowe *et al.* 2007; Lundqvist, 2013), type of residence (Holden & Gitlesen, 2006; Lowe *et al.* 2007; Jones *et al*. 2008) and age (Kiernan & Qureshi, 1993; Holden & Gitlesen, 2006), but not consistently across population studies.

The focus on correlates is important for its potential to provide a first level identification of likely risk factors for challenging behaviours. To date, correlates of challenging behaviour have been examined individually. We could locate no research, in population-based samples, on the cumulative impact of correlates. Following early work by Rutter (1979), evidence from non-ID populations is suggesting that behaviour problems are associated with *cumulative* risk, as opposed to individual risk factors acting independently (Appleyard, Egeland, van Dulmen & Sroufe, 2005). Being able to measure cumulative risk, and understand how variations in levels of cumulative risk may relate to challenging behaviour in adults with ID is important for the development of preventative intervention approaches.

The purpose of the present study was to estimate the prevalence of challenging behaviour in the total administrative population of adults with ID residing in Jersey. Jersey is an island measuring 118 square kilometres, 22 kilometres off the coast of Normandy, France. We aimed to build on available evidence from recent population studies (Jones *et al*. 2008; Lundqvist, 2013) by using a psychometrically sound behaviour assessment tool to define challenging behaviour. A second aim of the study was to examine socio-demographic correlates of challenging behaviours and explore methods of combining information about correlates into cumulative risk indices.

Method

Participants

Participants were 265 persons ≥ 18 years of age administratively defined as having ID (i.e., who were receiving, or had received, support from services in Jersey). Table 1 summarises participant characteristics.

Characteristic	**Summary statistic**
Mean age in years (SD)	41.44 (16.278)
Gender	Male: 134 (50.6%) Female: 131 (49.4%)
Type of accommodation	Congregate care: 108 (40.8%) Paid carer: 24 (9.1%) Family carer: 91 (34.3%) Independent living: 42 (15.8%)
Time in setting	Less than 1 year: 32 (12.1%) 1-5 years: 60 (22.6%) 6-10 years: 62 (23.4%) 11-20 years: 53 (20%) 21 years plus: 58 (21.9%)
Degree of intellectual disability	Profound: 26 (9.8%) Severe: 32 (12.1%) Moderate: 83 (31.3%) Mild: 124 (46.8%)
Other diagnoses (include)	Autism: 31 Down Syndrome: 36 Cerebral Palsy: 15 ADHD: 2 Fragile X: 2 Soto syndrome: 2 Other: 11
Daytime engagement	Paid work: 37 (14%) Voluntary work: 39 (14.7%) Vocational training: 22 (8.3%) Education: 5 (1.9%) Day service: 60 (22.6%) No daytime engagement: 102 (38.5%)
Epilepsy	57 (21.5%)
Psychiatric condition	70 (26.4%) including: Depression: 31 (11.7%) Schizophrenia: 18 (6.8%)

Table 1. Characteristics of participants

Procedure

Figure 2 presents an overview of the population ascertainment process. The Health and Social Services (H&SS) administrative database, in Jersey, FACE (Functional Analysis of Care Environments, 2012) was reviewed and 330 potential participants were identified. FACE records were then cross-referenced with current Education Department Record of Needs, and records of individuals maintained by local service providers from the voluntary sector and employment support services. This identified 52 additional individuals. A further 8 people were identified by researchers during the data collection process (new referrals to H&SS), providing 390 potential participants. Researchers screened all potential participants to ensure they met eligibility criteria. Persons were removed from the sample if they were deceased (N=13), had no ID diagnosis (from FACE records, N=45), were duplicate name entries on FACE (N= 9), had moved away permanently from Jersey (N= 8) or were below the age criterion (N= 4). This left 311 potential participants. Nine declined consent and a further 11 were traced but contact was not reciprocated. Some individuals were difficult to trace mainly due to minimal historical contact with services and their details were no longer accurate. Health and social care colleagues attempted to locate these individuals at the request of researchers and local death records were checked. Twenty six people were not traced. Surveys were completed with 265 participants which is equivalent to 97% of eligible and traceable participants (N=274) or 85% of eligible people (N=311).

Based on the most recent population census (2011), there are 78,342 adults over the age of 18 resident in Jersey. This suggests the administrative prevalence of ID is 0.40% in Jersey. The administrative ID prevalence estimate is similar to adult population ID estimates in other studies (0.33-0.48%: Jones *et al*. 2008; Lundqvist, 2013).

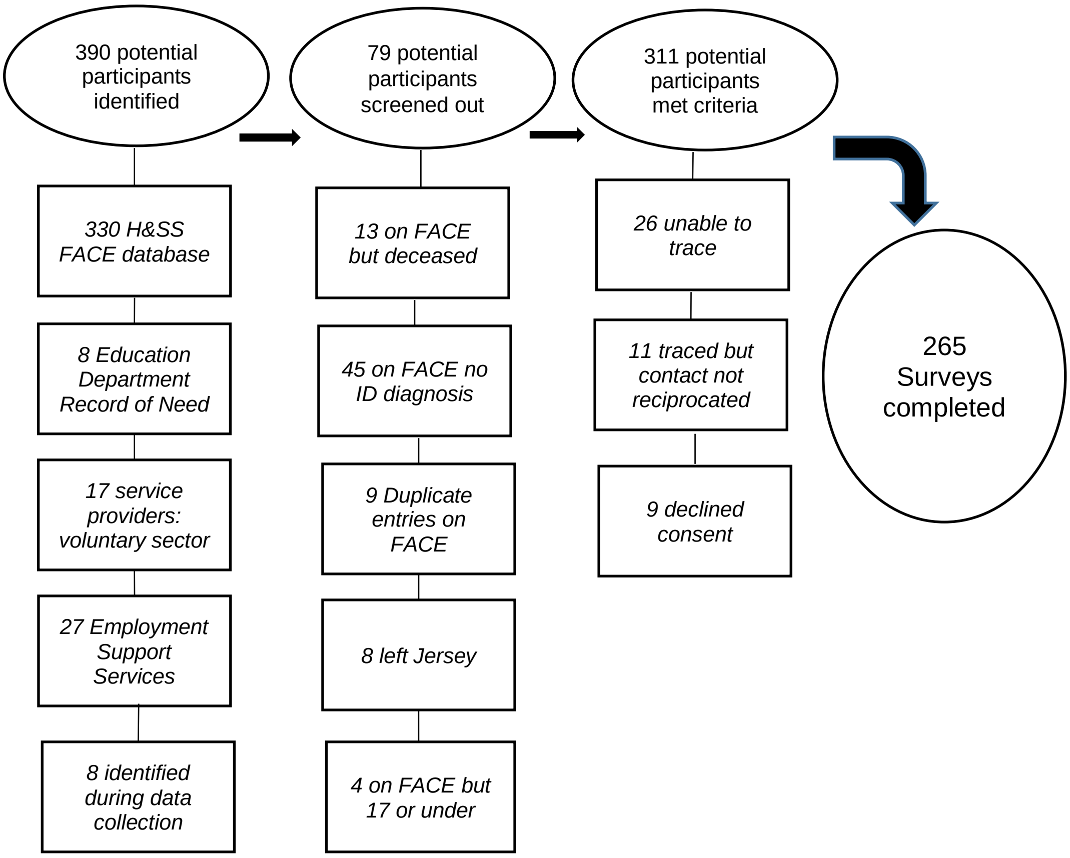

Figure 2. Flow diagram illustrating the population ascertainment process

Ethical approval

The study was approved by the University ethics committee (Appendix K), and by the States of Jersey, H&SS ethics committee (Appendix J). The consent process and accompanying documentation was designed using guidance from the Mental Capacity Act (2005) and the National Research Ethics Service (NRES; http://www.nres.nhs.uk/). The process and documentation for gaining consent are described in Appendices A to G. A lead professional was initially identified from the relevant databases who had previously supported the participant. Researchers met with the lead professional to complete a capacity assessment to determine whether the participant had the capacity to give consent to take part in this research (Appendix B). If the participant was assessed by the lead professional as not having capacity, a personal consultee was approached. If the participant was assessed as having capacity, this was further assessed face-to-face by researchers (Appendix C). If the participant was then assessed as not having capacity, a personal consultee was identified and approached and asked to consider consent using detailed study information provided (Appendix F). If the participant was assessed as having capacity, then a researcher completed the consent process with them alongside a witness (Appendix E). If participants, or their personal consultees, did not give consent, then they were not involved in the research project. Informed consent was obtained from 162 adults. For 103 adults who did not have capacity to provide independent consent, consultees gave consent.

Measures

A proxy informant was identified to complete the surveys for each participant. Informants were mainly either family members or key workers within a supporting organisation. All Informants who provided information about the participant had a minimum of regular weekly contact and had known the participant for at least one year. Researchers met face-to-face with proxy informants to complete the demographic survey and the Behavior Problems Inventory - Short Form (BPI-S).

1. Individual and Demographic Survey.

Individual and demographic data were gathered using a 22-item structured questionnaire (Appendix H) adapted from the Individual Schedule of the Challenging Behaviour Survey (Alborz, Bromley, Emerson, Kiernan & Qureshi, 1994) and the Wessex Scale (Kushlick, Blunden & Cox, 1973). Questions gathered information about the presence of Down syndrome, autism, dementia and any other syndromes / conditions; information about the degree of ID, formally recorded psychiatric disorders, epilepsy, sensory functioning, mobility, health, daytime engagement, and communication skills. Researchers selected most variables on an empirical basis due to their associations with challenging behaviour in previous studies. The Individual Schedule from the Challenging Behaviour Survey has been used in other population studies involving adults with ID (Holden & Gitlesen, 2006; Lowe *et al*. 2007) and has adequate inter-rater reliability (Emerson *et al*. 2001b; Lowe *et al*. 2007). The Wessex Scale has similarly been used in previous studies (Moss, Oliver, Arron, Burbridge & Berg, 2009) and there is evidence for good inter-rater reliability at subscale and item level (Kushlick *et al*. 1973; Palmer & Jenkins, 1982). Definitions for degree of ID were taken from the UK Department for Work and Pensions Guidance (2012). This definition categorises degree of ID based on IQ score (mild: 50-69; Moderate: 35-49; severe: 20-34;

profound: less than 20) and describes typical daily living skills and support needs associated with each category.

2. The Behavior Problems Inventory - short form for use with individuals with intellectual disabilities (BPI-S).

The BPI-S (Appendix I) was developed to measure challenging behaviours in adults with an ID presented during the previous six months (Rojahn *et al*. 2012a). The BPI-S is a shorter version of the Behavior Problems Inventory-01 (BPI-01) which has been used in a number of studies and shown to have good psychometric properties (Rojahn *et al*. 2001). The BPI-S has 30 questions in three categories. The self-injurious behaviour (SIB) subscale contains eight items, the aggressive-destructive behaviour (ADB) sub-scale ten items, and the stereotyped behaviour (SB) sub-scale twelve items. The BPI-S has two Likert-type rating scales per item – a five point frequency scale (never = 0; monthly = 1; weekly = 2; Daily = 3; Hourly = 4) and a three point severity scale (mild = 1; Moderate = 2; Severe = 3). A mild rated behaviour is defined as behaviour that does not cause significant damage to the individual or others, such as reddening of the skin, and any property damage does not require repair or replacement. A moderate severity behaviour is one that causes damage to the individual or others such as bruising or causes damage to the environment requiring repair. A severe impact behaviour is one that inflicts moderate to severe damage to the individual or others requiring medical intervention or causes damage to items which are beyond repair. Frequency and severity of behaviour are measured for the SIB and ADB subscales, and frequency alone for the SB subscale. A total frequency score can also be obtained across all items on the BPI-S, and a total severity score for ADB and SIB only.

The BPI-S has good psychometric properties (Rojahn *et al.* 2012b; Mascitelli *et al.* 2015). In the present study, Cronbach’s alpha for the total BPI-S frequency and severity scales was .891 and .773 respectively. The α-coefficient for the SIB subscale was .681 and .627 for the frequency and severity scale respectively. The α-coefficients for the ADB subscale were .792 and .788 for the frequency and severity scale respectively. The SB subscale, which only includes frequency ratings, had an α-coefficient of .867. Overall, internal consistency of the BPI-S was considered adequate to good depending on the domain measured. The comparatively lower α-coefficients for the SIB subscale have also been reported in previous studies, and may be related to either lower frequencies of behavioural topographies or ambiguity of the SIB construct (Rojahn *et al*. 2012b; Mascitelli *et al*. 2015).

Definition of challenging behaviour

To develop a definition of challenging behaviour, a working group of clinicians and researchers initially considered the BPI-S structure. Clinical experience highlighted the importance of considering both frequency and severity variables as considered in previous definitions of challenging behaviour – including Diagnostic Criteria with Learning Disabilities (DC-LD; Royal College of Psychiatrists, 2001). The definition was piloted initially to check that it could be applied to the BPI-S data before being finalised and used in the study to establish prevalence. The process of developing a definition was also informed by a comprehensive review of previous research from early studies that defined 'more' or 'less' challenging behaviour (e.g., Emerson *et al*. 2001a,b; Kiernan *et al.* 1997) and recent population studies such as Lundqvist (2013) who applied a clinical definition to the rating tool (Behavior Problem Inventory-01) utilised to collect data. Whereas Lundqvist (2013) only used severe-rated behaviour listed on the BPI 01, we felt this too restrictive and included a high-frequency element in all categories, especially as the SB scale on the BPI-S has no severity score. This led to a working definition of challenging behaviour, used to code behaviour problems as measured by the BPI-S:

a) SIB: Self-injurious behaviour is "challenging" if either it is rated as severe and occurs at least weekly, or is rated as moderate but occurs at least daily. Any other occurrence of self-injurious behaviour is not rated as challenging.
b) ADB: Aggressive destructive behaviour is "challenging" if either it is rated as severe and occurs at least weekly, or is rated as moderate but occurs at least daily. Any other occurrence of behaviour is not rated as challenging.
c) SB: Stereotyped behaviour is "challenging" if it occurs at the highest rated frequency (hourly). Any other occurrence of behaviour is not rated as challenging.
d) CB: Overall challenging behaviour is defined by the presence of a least one behaviour defined as "challenging" in the above categories.

Data analysis

Data were analysed using Statistical Package for the Social Sciences Version 21 (SPSS, Inc., Chicago, Il, US). The point prevalence of types of challenging behaviour (as defined above) was calculated with 95% confidence intervals.

To examine the association between demographic characteristics and challenging behaviour we followed two steps. In Step 1, we estimated a Relative Risk (RR) between each demographic indicator and challenging behaviour outcomes, as an indicator of their association. Variables from the demographic questionnaire were first cleaned and response categories collapsed, where appropriate. For example, response categories for incontinence (doubly incontinent, incontinent once a week or more, sometimes incontinent but less than once a week) were collapsed to create a binary variable ‘incontinent’ and ‘fully continent’. This process produced 19 dichotomous variables and 2 other continuous variables – age and time in the current setting (family, individual home, or service setting). RRs were calculated to explore the strength of association between each demographic factor and challenging behaviour outcomes. RR was calculated using the formula RR=(a/(a+b))/(c/(c+d)) for the four possible subgroups in a 2x2 table.

Correlate / risk variable	Present	Absent
CB present	a	b
CB absent	c	d

Table 2. Example of 2x2 table.

This formula is appropriate for binary outcomes. The 95% confidence intervals of the RR were computed using the formula RR=logRR±1.96×SE where SE(RR)=sqrt[1/a+1/c]-[1/(a+b)]-[1/(c+d)] (Altman, 1991). Where there were potential associations with continuous covariates, these variables were centred at their median value (Kraemer & Blasey, 2004). We then estimated RR using a Generalised Linear Model (GLM) where the exponentiated coefficient ‘b’ is equivalent to RR (Knoll, Le Cessie, Algra, Vandenbroucke & Groenwold, 2012).

In Step 2, we explored the strength of association between a cumulative number of demographic characteristics and challenging behaviour outcomes. For this, we used five different methods to create a cumulative risk index (CRI). In this step, we used 20 of the 21 potential correlates: living with a partner was removed from further consideration due to the very low numbers of people living with a partner.

CRIs are typically used to predict behavioural outcome following exposure to risk (Small & Luster, 1994; Evans, Dongping & Sepanski-Whipple, 2013). In this study, CRIs were not developed to predict any outcomes, as this is a cross-sectional study. Our aim was to explore the type of CRI that would demonstrate the strongest concurrent association with challenging behaviour. Such findings can then inform future longitudinal research, and clinical practice, that aims to predict and prevent challenging behaviour.

We first recoded all demographic indicators to binary variables, as CRIs are typically constructed by summing dichotomised risk factors (Evans *et al*. 2013). The two non-binary variables (Step 1 above) were thus recoded. Chronological age was dichotomised at 25 years. Under current UK service configuration, at 25 years of age individuals with ID transition from child to adult services. Time in setting indicated the length of time individuals had lived in their current residence and was dichotomised at 12 months, following an examination of the variable's distribution (Table 1) and on the basis that 12 months may be an adequate period for settling in following a move.

Apart from its potential clinical utility, this approach presents several methodological advantages over other approaches most commonly used, such as multiple regression. Firstly, collinearity between risk factors does not distort estimates of multiple risk in the CRI model (Evans *et al*. 2013). Where regression models may reject certain risk factors in the final model, the CRI can accommodate independent and interdependent risk factors (Evans *et al*. 2013). Having multiple, correlated predictors in a regression model can affect estimates and reduce statistical power (Myers & Wells, 2003). Additionally, CRIs are parsimonious and statistically sensitive even with small samples (Cohen, Cohen, West & Aiken, 2003; Evans *et al*. 2013).

Five CRIs were constructed as follows:

CRI Method 1. All 20 available demographic variables were considered. Participants received a score of '1' for each 'risk' indicator present and '0' if absent (e.g. non-verbal=1, verbal=0). The number of factors present for each participant was estimated with 20 as the potential maximum value of the CRI.

CRI Method 2. A weighted CRI was calculated by multiplying each participant's CRI (Method 1) with the relevant RR scores produced for each challenging behaviour outcome. The summation of these scores produced a weighted CRI for each challenging behaviour. Where the initial CRI summed the number of 'risk' factors present, this weighted CRI also accounts for the intensity of risk exposures.

CRI Method 3. An outcome-specific CRI was created by summing the number of factors identified in step 1 as having a RR equal to or larger than 1.5 for each challenging behaviour category. Therefore, each challenging behaviour outcome had a different CRI, depending on which of the 20 factors was univariately associated with a strength of (RR) 1.5 or higher.

CRI Method 4. A cumulative domain risk index (CDRI) was constructed not by considering individual ‘risk’ factors as in the previous methods, but by grouping individual factors in conceptually coherent domains of ‘risk’: (a) personal characteristics: age, gender; (b) diagnostic status characteristics: degree of ID, autism present, Down syndrome present, other syndrome present, psychiatric disorder, dementia; (c) placement characteristics: type of residence, time in setting, daytime engagement; (d) communication skills: presence of speech, speech clarity, understanding of communication; and (e) physical and sensory health: continence, mobility, epilepsy, seizures, vision and hearing. We examined whether any risk factor was present (1 vs 0) within each domain, and then created a CDRI by summing the number of domains where at least one ‘risk’ was present (range of CDRI scores 0-5). This method aimed to explore the suggestion that adverse outcomes come about when individuals are exposed to a higher number of risk domains (Campbell, Shaw & Gilliom, 2000).

CRI Method 5. A weighted CDRI was calculated by multiplying the number of ‘risk’ variables present within each risk domain (Method 4) by the total number of ‘risk’ variables within the domain, and dividing by the overall number of ‘risk’ variables available (i.e. 20). For example, the communication domain included three variables. If the participant scored yes to two of these the weighting would involve (2*3)/20. The summation of these results from each domain produced the weighted CDRI. This method is conceptually similar to method 4, but aims to account for any high concentration of ‘risk’ within a domain.

To explore the strength of the association between each different CRI type and challenging behaviour outcomes, we fitted Receiver Operating Characteristic (ROC) curves and compared the resulting Area Under the Curve (AUC) scores between methods. AUCs are equivalent to the Wilcoxon test of ranks (Hanley & McNeil, 1982) and an informative effect size denoting clinical significance (Kraemer *et al*. 2003).

Results

Prevalence of challenging behaviour

Using the definitions derived from BPI-S responses (see above) 18.1% of participants presented challenging behaviour (CB) (n=48) (95% CI: 13.94%-23.19%), 7.5% (n=20) presented SIB (95% CI: 4.94%-11.37%), 8.3% (n=22) presented ADB (95% CI: 5.54%-

12.25%), and 10.9% (n=29) presented SB (95% CI: 7.73%-15.27%). Table 2 lists the most prevalent topographies within each subtype.

Category	**Specific behaviour**	**Prevalence (%)**	**95% CI**
Self-injurious behaviour (SIB)	SIB Total	7.5	4.94-11.37
	Self-scratching	3.0	1.54-5.84
	Head hitting	2.3	1.04-4.85
	Hair pulling	1.9	0.81-4.34
	Teeth grinding	1.9	0.81-4.34
Aggressive destructive behaviour (ADB)	ADB Total	8.3	5.54-12.25
	Verbally abusive	4.2	2.33-7.28
	Biting others	2.3	1.04-4.85
	Bullying	2.3	1.04-4.85
Stereotyped behaviour (SB)	SB Total	10.9	7.73-15.27
	Repetitive hand or finger movements	5.7	3.46-9.13
	Rocking / repetitive body movements	3.4	1.8-6.33
	Pacing, jumping, bouncing, running,	2.6	1.28-5.35
	Yelling and screaming	2.6	1.28-5.35
	Waving or shaking arms	2.6	1.28-5.35

Table 3. Prevalence of specific behaviours

Correlates of challenging behaviour - Relative Risks

Figures 3 to 6 displays the results from the initial relative risk (RR) analysis on the association between each demographic characteristic with challenging behaviour outcomes. RRs above 1 indicate an elevated risk of presenting challenging behaviour, whereas RRs below 1 indicate a reduced risk of challenging behaviour. Where 95% confidence intervals for the RR included 1, the RR was deemed not statistically significant. It is important to note that this is a cross sectional design and the factors described here are those associated with higher levels of challenging behaviour in this sample. It cannot be determined whether they are a cause or effect of the behaviour described in this model. Three characteristics were systematically and significantly associated with all four categories of challenging behaviour (SIB, ADB, SB and overall CB). These were being non-verbal, having limited understanding of communication and having a severe-profound ID (RRs ranged from 2.471 to 12.16). Living in paid or congregate care, the presence of an autism diagnosis, having no daytime engagement, the presence of another syndrome, impaired vision, no clear speech, incontinence, the presence of seizures, epilepsy and mobility problems were significantly associated with some topographies of challenging behaviour, but not consistently across all categories. Age, gender, living with partner, Down syndrome, time in current setting, impaired hearing, dementia or psychiatric disorder were not significantly associated with challenging behaviour. (Please note that due to variations in the size of confidence intervals there are different scale lengths on each x-axis in Figures 3-6).

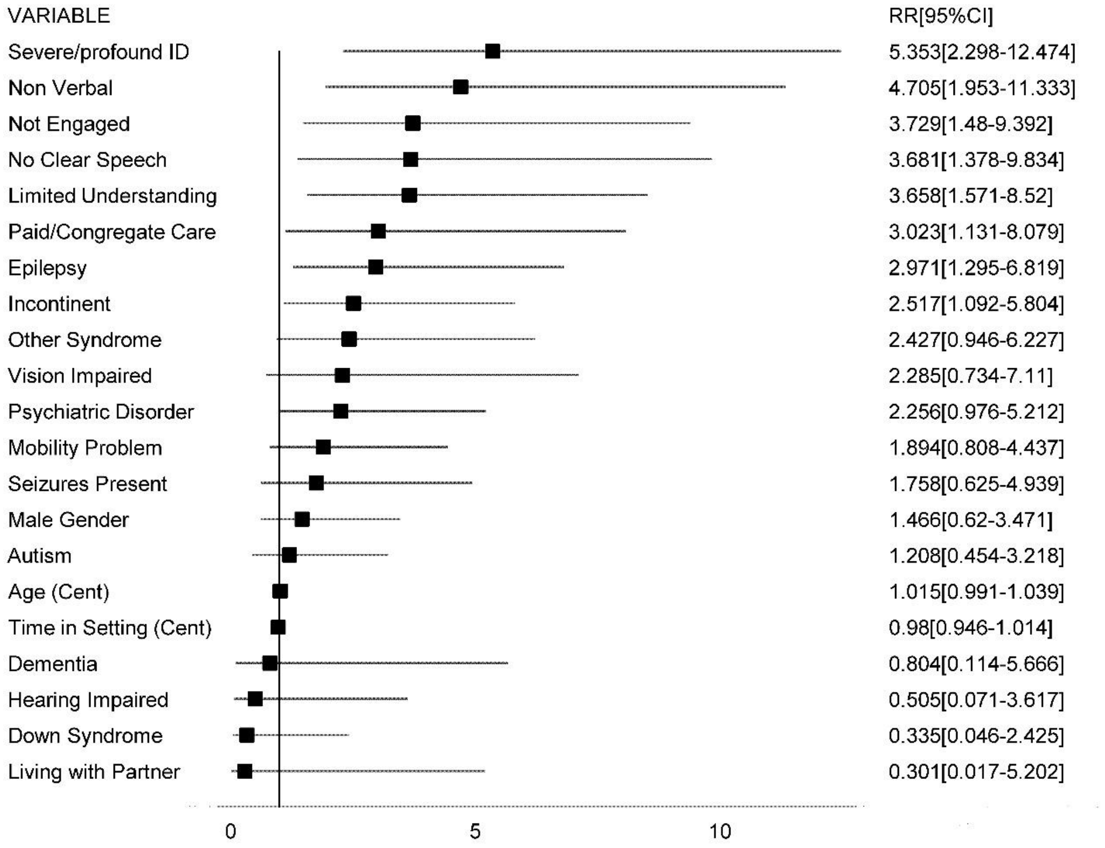

Figure 3. Forest plot illustrating Relative Risk (95% CI) between demographic factors and self-injurious behaviour

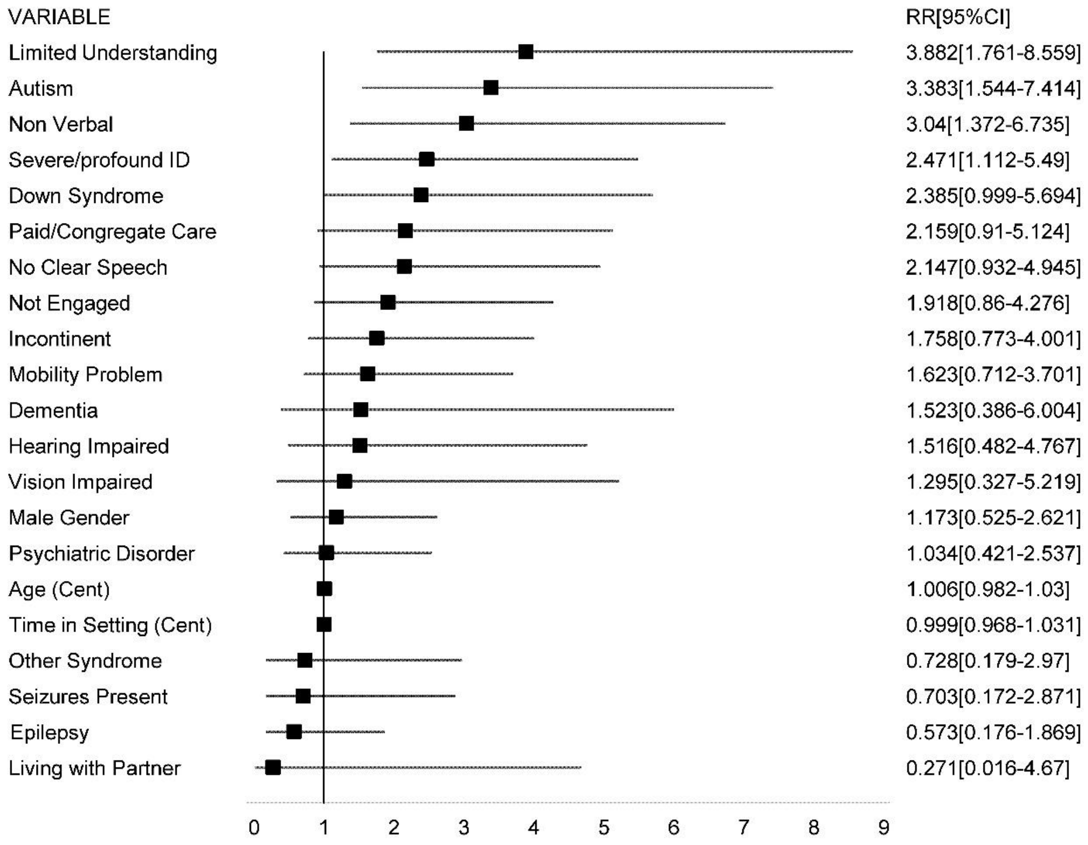

Figure 4. *Forest plot illustrating Relative Risk (95% CI) between demographic factors and aggressive destructive behaviour*

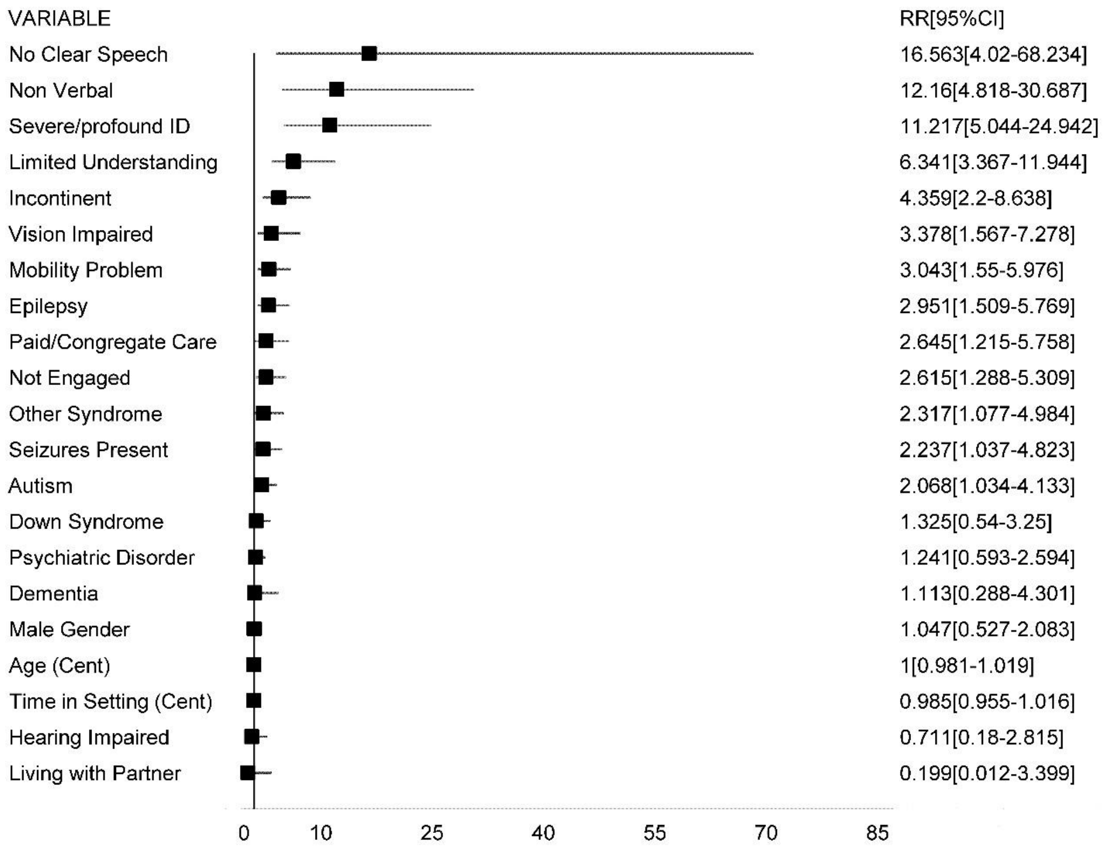

Figure 5. Forest plot illustrating Relative Risk (95% CI) between demographic factors and stereotyped behaviour

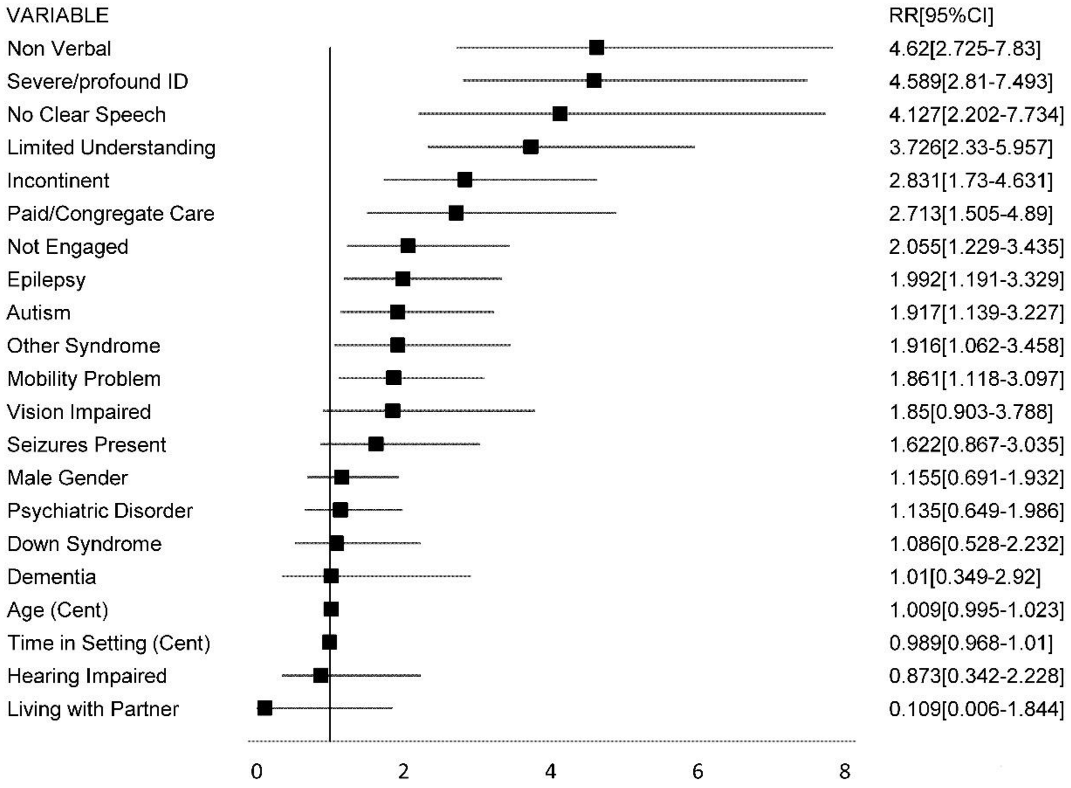

Figure 6. Forest plot illustrating Relative Risk (95% CI) between demographic factors and overall challenging behaviour

Cumulative Risk Indices (CRIs)

Having identified pairwise associations between demographic variables and challenging behaviour, we compared five methods of constructing CRIs. Where demographic characteristics explored were continuous variables (as was the case for age and years living in setting), the first step was to obtain RRs on binary versions of these variables. The RRs for these binary versions were as follows: For age RR (95%CI) = SIB: 0.819 (0.284-2.358); ADB: 0.963 (0.37-2.504); SB: 1.042 (0.467-2.322); overall CB: 0.862 (0.456-1.627). For time in current setting RR (95%CI) = SIB: 0.809 (0.197-3.325); ADB 1.618 (0.584-4.48); SB: 1.165 (0.433-3.131); overall CB: 1.04 (0.481-2.25).

Table 3 presents the AUCs resulting from the ROCs. As indicated by the magnitude and confidence intervals of the AUCs there was little variation among the five methods.

AUCs close to 1 indicate that the CRI method accurately distinguishes between participants with challenging behaviour and no challenging behaviour. AUC scores closer to 0.5 indicate the CRI provides a risk prediction that is no better than chance (Zhou, Obuchowski & Obuchowski, 2002). Each CRI method performed resulted in a statistically significant AUC that was reasonably strongly associated with SIB (AUCs ranged from .719 to .756), ADB (AUCs ranged from .687 to .730) and overall CB (AUCs ranged from .750 to .784), and very strongly with SB (AUCs ranged from .827 to .891). The weighted CRI (Method 2) produced the largest AUCs (Table 3), however, these were not significantly better than AUCs produced by any of the other methods as indicated by overlap in confidence intervals.

Area Under the Curve (AUC)										
Method		**Range**	**Mean**	**SD**	**Behaviour**	**AUC**	**Asymp sig.**	**SE**	**Asymptotic 95% CI**	
									Lower Bound	**Upper Bound**
1.	**CRI**	0-13	4.65	2.96	SIB	.742	<.001	.064	.616	.867
					AD	.703	.002	.056	.594	.812
					SB	.869	<.001	.034	.802	.935
					CB	.767	<.001	.041	.687	.846
2.	**Weighted CRI**	0-39	12.04	9.53	SIB	.756	<.001	.064	.630	.882
		0-24	8.54	6.19	AD	.730	<.001	.054	.624	.837
		0-71	21.8	20.7	SB	.891	<.001	.026	.840	.941
		0-35	10.9	8.86	CB	.784	<.001	.039	.708	.859
3.	**Custom CRI**	0-13	3.77	2.83	SIB	.751	<.001	.063	.628	.874
		0-10	3.11	2.55	AD	.724	.001	.056	.614	.833
		0-12	3.23	2.75	SB	.874	<.001	.030	.816	.932
		0-12	3.23	2.75	CB	.778	<.001	.038	.704	.852
4.	**CDRI**	0-5	2.88	1.27	SIB	.719	.001	.061	.599	.838
					AD	.687	.004	.055	.579	.796
					SB	.827	<.001	.035	.759	.895
					CB	.750	<.001	.039	.674	.826
5.	**Weighted CDRI**	0-2.95	0.96	0.69	SIB	.731	.001	.064	.605	.858
					AD	.696	.002	.055	.588	.804
					SB	.861	<.001	.033	.795	.927
					CB	.759	<.001	.040	.680	.838

Table 4. Area under the curve scores

Discussion

The overall prevalence of challenging behaviour in adults with ID in Jersey was 18.1% (95% CI: 13.94%-23.19%). This is similar to other adult population studies that have used behaviour assessment tools designed for adults with ID (Jones *et al.* 2008: 18.7%-22.5%; Lundqvist, 2013: 18.7%).

The prevalence of discrete subtypes of challenging behaviour is seldom reported in total population samples. In the present sample, stereotyped behaviour (SB) was the most common behavioural form (SB = 10.9%) followed by aggressive-destructive behaviour (ADB = 8.3%) and self-injurious behaviour (SIB = 7.5%). High rate stereotyped behaviour can have a significant negative impact on quality of life and requires further investigation. The prevalence of stereotypy has been considered in only one other population study (Lundqvist, 2013) and was estimated at 6.1%. Other studies have reported ADB as the most prevalent behavioural form, followed by SIB (e.g., Cooper *et al*. 2009ab: ADB 9.8%, SIB 4.9%; Lundqvist, 2013: ADB 11.9%, SIB 8.4%). The present study also suggests that ADB appears to be more prevalent than SIB.

Three characteristics were significantly associated with all subtypes of challenging behaviour. These were non-verbal speech, limited understanding of verbal communication, and severe-profound ID. Communication impairments have been previously associated with challenging behaviour (Kiernan *et al.* 1997; Emerson *et al*. 2001ab; McClintock, Hall & Oliver, 2003; Holden & Gitlesen, 2006; Lundqvist, 2013). In the present study, 119 (45%) participants had an impairment of expressive communication (75 were non-verbal and 44 had impaired clarity of speech). Seventy-three (27.5%) had limited receptive understanding of communication. However, only 32 (12%) had augmentative alternative communication (26 used Makaton, 3 the Picture Exchange Communication System (PECS), 2 British Sign Language (BSL) and 1 an iPad application). Even when a person knew Makaton, it was not always clear whether their carers / staff were competent in its interpretation or use. Improving the ability of adults with ID and others to communicate effectively will be vital given the association between impaired communication and challenging behaviour. The association between degree of ID and challenging behaviour also supports previous research (Emerson & Bromley, 1995; Kiernan *et al*. 1997; Emerson *et al*. 2001ab; McClintock *et al*. 2003; Holden & Gitlesen, 2006; Jones *et al*. 2008; Lundqvist, 2013).

A strong association was seen between lack of daytime engagement and self-injury (RR=3.729) and stereotypy (RR=2.615). Although the cross-sectional design of the present study cannot determine whether lack of engagement is a cause or effect of SIB/SB, 38.5% of participants in this study had no daytime engagement. This is high but similar to previous estimates of one-third (Lowe *et al*. 2007), emphasising the need to increase levels of meaningful engagement.

Living in paid / congregate care (associated with SIB and SB here) has been reported as an associate of challenging behaviour in other studies (Holden & Gitlesen, 2006; Lowe *et al.* 2007; Jones *et al*. 2008). Incontinence (associated with SIB and SB) has been related to aggression in previous studies (Cooper *et al*. 2009ab), suggesting future research attention is warranted. Epilepsy (associated with SIB and SB) has been related to challenging behaviour in some studies (Deb, Thomas & Bright, 2001), but not in recent population-based samples (Jones *et al*. 2008; Lundqvist, 2013). Autism (associated with ADB and SB) has also been associated with challenging behaviour in previous research (McClintock *et al*. 2003; Lundqvist, 2013).

There was an equitable gender distribution in this sample (50.6% male, 49.4% female). This may be explained by the fact there was a greater proportion of men not included in the study either because researchers were unable to trace them, they did not reciprocate contact, or they declined consent (33 males vs. 13 females). It should be noted, however, that the precision of gender estimates in population studies is unknown because of lack of confidence intervals (e.g., 562 [54.9%] men, 461 [45.1%] women: Jones *et al*. 2008). Of interest was also the lack of gender differences in the prevalence of challenging behaviour, contrary to findings in other studies (e.g., Emerson *et al.* 2001a; Jones *et al*. 2008). However, population studies with a similarly wide age range and larger sample (18–87 years, n = 915; Lundqvist, 2013) also did not identify gender differences for most challenging behaviour categories. It is likely that the reported variability regarding gender differences in the literature is related to studies' sampling designs, participant age, and gender ratio.

The findings on correlates may highlight populations at risk of developing challenging behaviour. We extended this work by building exploratory CRIs and by testing different methods of constructing these. The aim of our approach was to identify a method of developing a CRI that clinical services will be able to use in the future (following longitudinal replication to establish its predictive validity) to predict the risk of presenting challenging behaviours and design interventions targeting multiple risk factors. Identifying adults with multiple risk factors is likely to identify vulnerable adults who are a priority for interventions and addressing multiple rather than singular risks is likely to prove more efficacious (Evans *et al*. 2013). Our results indicated that any type of CRI was reasonably associated with challenging behaviour including the potentially service-friendly, uniform, additive CRI (Method 1). The advantage of this CRI method is that it could be developed into a user-friendly, easily interpreted tool for professionals to use in practice thus avoiding the need for more complex analysis. Weighting the CRIs as in methods 2 and 5 was associated with slightly better estimates, but the differences were not statistically significant from the simpler additive methods. The fact that the different CRI methodologies resulted in similar findings is potentially useful practically and was important to examine in this research. Until prospective data is available, it is unclear how valuable and robust the methodological approach is.

Some of the observed variation in AUCs is related to differences in the range of scores of each CRI method. The largest AUC was obtained for the weighted CRI which has the longest scale range. Using the weighted method, SB had the highest AUC score (.891) and the longest scale range (0-71) and ADB the lowest AUC score (.730) and the narrowest range (0-24). Similarly, the lowest AUC scores are seen in the CDRI (Method 4) which has the narrowest range (0-5). The CDRI and weighted CDRI, which were calculated using subgroups of risk factors, might be useful for future risk management as opposed to risk prediction. It should be noted that AUCs in this study were used to explore the potential association, not as a risk prediction test. The latter requires testing in a prospective study. Future longitudinal research is required to replicate these analyses before concluding about the CRI method with the highest predictive validity.

There are four main limitations of the present study. First, study findings apply only to the administratively defined population with ID in Jersey, as other adults with IQ < 70 in the community and not known to services were not included. Those with complex presentations, physical health problems, mental health problems or challenging behaviour may have greater support needs, be more likely known to services, and thus over-represented in the sample. However, findings from this study are likely useful in practice as specialised support (such as for challenging behaviour) might be best planned on the basis of a population of people with ID already known to services. Further, the concept of defined challenging behaviour may not be a useful fit for those who do not use services. A previous meta-analysis indicated an adult ID prevalence rate of 4.94 / 1,000 (95% CI: 3.66–6.22) (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011) which would indicate that 80% of adults with ID in Jersey are listed on the FACE database. Whilst the sample size in this study (n=265) is lower than other recent population samples (e.g. Jones *et al.* 2008: n=1023; Lundqvist, 2013: n=915), given that surveys were completed on 85% of eligible participants results are a robust representation of the Jersey population in receipt of ID services. Secondly, the FACE database was checked to explore whether participants had a record of a cognitive assessment or psychiatric diagnosis. Where they did not there was a reliance on proxy informants to identify level of ID and psychiatric diagnosis. There was a descriptive key listing typical presentations associated with level of ID (ability to complete tasks of daily living and support needs) taken from the Department of Work and Pensions (2012) definition to support informants with this. The third limitation is that the cross-sectional design enabled factors currently associated with challenging behaviour to be identified for the whole cohort, but these variables may not have been those conferring risk for the development or maintenance of challenging behaviour over time. Finally, the list of potential risk factors investigated may not be exhaustive. Factors such as socio-economic position, traumatic life events, quality of environments, and other psychosocial factors may contribute. Whilst there are methodological difficulties in assessing these, a potential impact should be acknowledged. The number of population-based studies is small, and they have multiple differences in terms of population, sample size, age, definitions, behaviours included, and research tools utilised. There is currently no clear way to systematically evaluate the impact of these methodological differences on prevalence data (e.g., via meta-analysis) because of the very small number of population-based studies. With more population-based studies published, this will be a valuable exercise in future. In summary, the present study identified the total administrative population of adults with ID in a defined geographical area and measured challenging behaviour with a well-validated tool that is appropriate for people with ID. The estimated prevalence of behaviour problems was similar to estimates provided in other recent population studies (Jones *et al*. 2008; Lundqvist, 2013). Communication difficulties and severity of ID were consistently associated with a higher risk of presenting any type of challenging behaviour. These findings highlight the hypothesized function of challenging behaviour as a communicative act, and point to specific subgroups that are more susceptible to presenting high levels of behaviour problems. Last, the study compared different methods of measuring cumulative risk, a method that has implications for clinical practice. Our findings indicated that CRIs are significantly associated with challenging behaviours and, subject to longitudinal replication, any method of CRI can measure risk with a similar potency.

CHAPTER 3

Prevalence of psychotropic medication use and association with challenging behaviour in adults with an intellectual disability. A total population study[2].

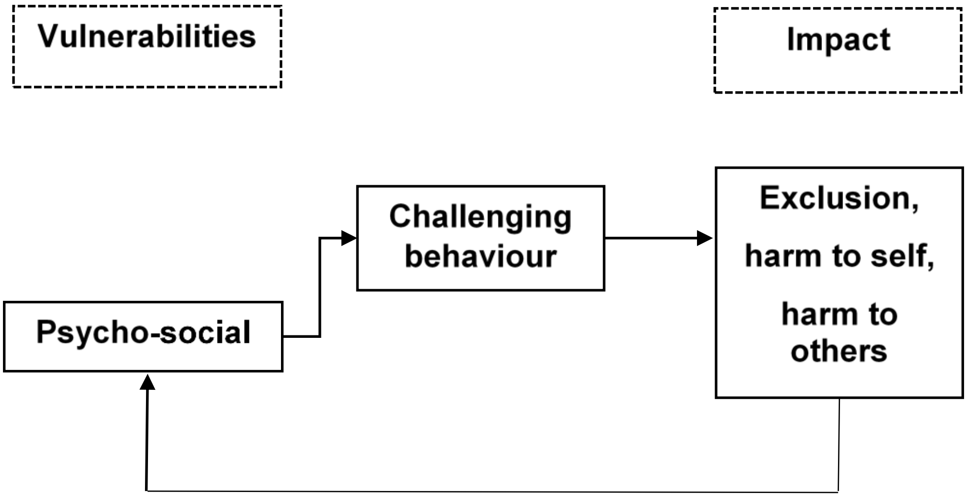

Figure 1. Impact: Framework for understanding why challenging behaviour occurs (Hastings et al. 2013).

Chapter 2 indicated that challenging behaviour was common in adults with ID and the focus of chapter 3 is on one potential impact of this not currently considered in the framework for understanding challenging behaviour (Figure 1) – a high level of psychotropic medication use. Recent UK research has indicated that about half of adults with ID are prescribed psychotropic medication (Sheehan *et al.* 2015; Henderson *et al*. 2015) and higher prevalence of psychotropic medication is associated with challenging behaviour (Gothelf *et al*. 2008; Matson & Neal, 2009; Henderson *et al*. 2015; Sheehan *et al.* 2015). This chapter focuses on

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[2] A version of this chapter was published as: Bowring, D. L., Totsika, V., Hastings, R. P., Toogood, S., and McMahon, M. (2017) Prevalence of psychotropic medication use and association with challenging behaviour in adults with an intellectual disability. A total population study. Journal of Intellectual Disability Research, 61: 604–617.

the prevalence of psychotropic medication use in adults with ID in Jersey and the associated factors. Very few population studies have explored the prevalence of psychotropic medication use in adults with ID and those that exist have used varying medication classification systems to make comparisons difficult. Further, existing studies have used varying definitions of challenging behaviour and not used psychometrically evaluated tools to classify and measure challenging behaviour. This chapter addresses the limitations of previous studies and extends research by describing patterns of prescribing associated with various topographies of challenging behaviour.

Abstract

Background. There is a high prevalence of psychotropic medication use in adults with Intellectual Disabilities (ID), often in the absence of psychiatric disorder, also associated with challenging behaviour. Previous research has focused on specific sample frames or data from primary care providers. There is also a lack of consistency in the definition of challenging behaviour used.

Methods. We adopted a total population sampling method. Medication data on 265 adults with ID were classified according to the Anatomical Therapeutic Chemical classification system. The Behaviour Problems Inventory – short form classified challenging behaviours. We examined the association between challenging behaviour and the use of psychotropic medication, and whether any association would still be present after accounting for socio-demographic and clinical characteristics.

Results. 70.57% of adults with ID were prescribed at least one class of any medication (mean per person =2.62; range 0–14). Psychotropic medications were used by 37.73% of participants with antipsychotics the commonest type used by 21.89% of individuals. Polypharmacy and high dosages were common. Generalised Linear Models indicated significant associations between psychotropic medication and the presence of a psychiatric diagnosis, challenging behaviour, older age and type of residence. Male gender was additionally associated with antipsychotic medication.

Conclusions. The use of a total population sample identified via multiple routes is less likely to overestimate prevalence rates of medication use. Current challenging behaviour was a predictor of medication use after controlling for other variables. Data indicate that there may be differences in prescribing patterns associated with different topographies of challenging behaviours.

Keywords. antipsychotic, Behaviour Problems Inventory, challenging behaviour, intellectual disability, Psychotropic medication.

Introduction

Psychotropic medication, and in particular antipsychotic medication, is overused in people with intellectual disabilities (ID) (Deb & Fraser 1994; Sheehan *et al*. 2015). Studies have reported varied prevalence and patterns of prescribing. For example, UK estimates vary from 49% (Sheehan *et al.* 2015) to 89% (Deb *et al.* 2014) with some variation subject to residence or setting of the sample cohort (Robertson *et al*. 2000; Tsiouris *et al*. 2013). Antipsychotics have been reported to be the most common type of medication prescribed to individuals with ID (Holden & Gitlesen, 2004; Deb & Unwin, 2007; Matson & Neal, 2009; Singh & Matson 2009; Henderson *et al*. 2015; Sheehan *et al.* 2015). Up to 62% of adults with ID who receive psychotropic medication receive multiple psychotropic medications (Lott *et al.* 2004) often in high dosages (Cullen 1999; McGillivary & McCabe, 2004; Deb *et al.* 2009; Taylor 2010). Some increased medication use may be explained by a high prevalence of psychiatric problems in adults with ID as suggested in some studies (Chaplin 2004; Cooper et al. 2007; Morgan et al. 2008; Buckles et al. 2013). Caution should be taken with this conclusion given shortcomings in studies that have explored prevalence of psychiatric problems in adults with ID such as the focus on specific samples, variations in how diagnoses are obtained, few non-ID population control groups (Whitaker & Read, 2006) and the inclusion of behavioural problems as a psychiatric category in some studies (e.g. Cooper, 1997). There are also difficulties with diagnosing individuals with ID with mental health issues, such as bipolar disorder, largely because of limitations in communication, and ability to readily express feelings and thoughts (Cain *et al*. 2003). However, prescribing rates are typically higher than reported rates of mental health problems (Henderson et al. 2015; Sheehan et al. 2015) and prescribing is also associated with the presence of challenging behaviour (Gothelf et al. 2008; Matson & Neal 2009; Henderson et al. 2015; Sheehan et al. 2015).

In studies that have used convenience or small samples recruited from clinical services, estimates of the prevalence of the use of psychotropic medication have been high. For example, in a community based sample of adults with ID and aggressive behaviour, from ten psychiatric clinics in the West Midlands, UK, 89% were prescribed psychotropic medication (Deb *et al.* 2014). Similarly, 72% of adults with ID at a Psychiatry Department in Salford, UK, were prescribed antipsychotics (Griffiths *et al.* 2012). Data from such samples are likely to be associated with a range of biases and total population or population representative samples are needed. Henderson *et al.* (2015) focused on a prospective cohort sample of 1023 adults aged ≥16 years with ID known to local services including primary care (general practitioners – GPs) in Scotland. Sheehan *et al*. (2015) identified 32306 adults aged ≥18 years with ID from 3.7 million active patients on The Health Improvement Network (THIN) where records from 571 General Practices were examined. Henderson *et al.* (2015) found a 49.1% prevalence rate of psychotropic medication use with a prevalence rate of antipsychotic drug use of 23.2%. Similarly, Sheehan *et al*. (2015) found a 49% prevalence of psychotropic medication use with 21% of participants prescribed antipsychotic medication. These studies used population-based samples, but identified their participants from primary care services.

Some studies have found that adults with challenging behaviour are prescribed more psychotropic medications than those without challenging behaviour (Holden & Gitlesen, 2003; Aman & Ramadan, 2007; Crossley & Withers 2009; Doan *et al.* 2013; Scheifes *et al.* 2015). In the Henderson *et al.* (2015) study, 32% of those prescribed antipsychotics had no mental health problems at the time of assessment. Sheehan *et al.* (2015) reported that 47% of participants with a record of challenging behaviour received antipsychotics but only 12% had a record of mental illness. There remains no convincing evidence of positive treatment effects of these medications on challenging behaviour (Emerson & Baines, 2010; Tsiouris 2010; Paton *et al.* 2011; Wilner 2014). The underlying aetiological factors for challenging behaviour are complex and varied (Hastings *et al*. 2013) so treatment with medication alone is unlikely to resolve the issue. Under current UK best practice guidelines (NICE 2015; RCP 2016) if adults with ID and challenging behaviour have no evidence of mental illness then there may be no role for prescribing, other than in the very short term to address risk whilst other psychosocial interventions are implemented.

Socio-demographic factors associated with higher prevalence rates of psychotropic medication are male gender (McGillivray & McCabe, 2006; Delafon *et al.* 2013; Doan *et al.* 2014) and older age (Holden & Gitlesen, 2004; Singh & Matson, 2009; Deb *et al.* 2014; Sheehan *et al.* 2015). Kiernan *et al.* (1995) found different prevalence rates in different districts of the UK and hypothesised that this may be due to different organisation in psychiatric services for people with ID. Variation in prevalence rates by residential setting has also been identified with highest prevalence rates in hospitals, lower in community residential services and lowest in family homes (Clarke *et al.* 1990; Kiernan *et al.* 1995; Robertson *et al*. 2000; Tsiouris *et al*. 2013).

Further research is thus required for several reasons. First, obtaining accurate prevalence rates of psychotropic drug use has been problematic given many existing studies have focused on small, highly selective convenience samples with a lack of population-wide estimates (Sheehan *et al.* 2015). The number of population-based studies is small with participants recruited predominantly from primary care. One of the limitations of the Sheehan *et al*. (2015) study was the potential under-recording by GPs of people with mild ID. This may have overestimated the prevalence of prescribing given potentially lower levels of challenging behaviour (Bowring *et al.* 2017a / chapter 2) and psychiatric problems (Whitaker & Read, 2006) in this sub-group. One disadvantage of using data from primary care is the lack of reliable and consistent identification of adults with an ID. Second, there has been variation in results due to a lack of standardised medication rating systems, preventing comparisons between studies. For example, some researchers have included antiepileptics for epilepsy as psychotropic medications (Holden & Gitlesen, 2004; Henderson *et al.* 2015), whereas other researchers have classed them as somatic medication (Scheifes *et al.* 2013; Doan *et al*. 2014). Third, researchers have used varied definitions of challenging behaviour to examine its putative association with medication use. Sheehan *et al*. (2015) used a 200 long list of behaviours, including sleep disturbance, which primary care providers coded against records. This system was not externally validated, it was not clear if all behaviours would be reported to GPs and did not identify if the problem was historical or current. Sheehan *et al*. (2015) reported that 36% of participants had a record of challenging behaviour with the majority of codes featuring generic labels such as ‘behaviour problem’ or ‘behaviour disorder’ with few specific topographical codes used. This rate of challenging behaviour is considerably higher than reported in other recent population studies (Bowring et al. 2017a / chapter 2: 18.1%; Jones *et al*. 2008: 18.7%–22.5%; Lundqvist, 2013: 18.7%). Behaviour may be more accurately assessed through a direct individual assessment utilising a psychometrically evaluated behaviour rating scale with clear definitions of what constitutes challenging behaviour taking into account temporal and intensity factors.

The main aim of the present study was to address these limitations in existing studies by investigating the prevalence of medication use, particularly psychotropic medication, in the total administrative population of adults with ID (identified through multiple methods) in Jersey, Channel Islands. We determined the prevalence of psychotropic medication using an internationally recognised coding system (the World Health Organisation Anatomic Therapeutic Classification Scheme – WHO 2014; WHOCC –ATC/DDD, 2014) and examined associations with challenging behaviour, and specific sub-types of challenging behaviour, identified by a rating tool with good psychometric properties (the Behaviour Problems Inventory – short form; Rojahn *et al.* 2012a, b). We also explored whether any association between medication prescription and challenging behaviour would be present after accounting for other socio-demographic and clinical characteristics.

Method

Participants

Participants were 265 persons ≥ 18 years of age administratively defined as having ID (i.e., who were receiving, or had received, support from services in Jersey, Channel Islands). Participants were identified from multiple sources including the Health and Social Services (H&SS) administrative database, in Jersey, FACE (Functional Analysis of Care Environments, http://www.face.eu.com). FACE is a database used by the local community multi-disciplinary ID service which includes social work, occupational therapy, community nursing, positive behaviour support service and physiotherapy. Records were cross-referenced with current Education Department Record of Needs, and records of individuals maintained by local service providers from the voluntary sector and employment support services. The population ascertainment process and more detail on the procedure is provided in a previous paper (Bowring *et al.* 2017a / Chapter 2). Table 1 summarises participant characteristics. Of the 265 participants 50.6% (n=134) were male and 49.4% (n=131) female with a mean age of 41.44 (range 18-85 years). The majority lived in either congregate care (40.8%) or with family (34.3%). Over a quarter of adults (26.4%) had a psychiatric condition.

Characteristic	Summary statistic
Mean age in years (SD)	41.44 (16.278)
Gender	Male: 134 (50.6%) Female: 131 (49.4%)
Type of accommodation	Congregate care: 108 (40.8%) Paid carer: 24 (9.1%) Family carer: 91 (34.3%) Independent living: 42 (15.8%)
Time in setting	Less than 1 year: 32 (12.1%) 1-5 years: 60 (22.6%) 6-10 years: 62 (23.4%) 11-20 years: 53 (20%) 21 years plus: 58 (21.9%)
Degree of intellectual disability	Profound: 26 (9.8%) Severe: 32 (12.1%) Moderate: 83 (31.3%) Mild: 124 (46.8%)
Other diagnoses (include)	Autism: 31 Down Syndrome: 36 Cerebral Palsy: 15 ADHD: 2 Fragile X: 2 Soto syndrome: 2 Other: 11
Daytime engagement	Paid work: 37 (14%) Voluntary work: 39 (14.7%) Vocational training: 22 (8.3%) Education: 5 (1.9%) Day service: 60 (22.6%) No daytime engagement: 102 (38.5%)
Epilepsy	57 (21.5%)
Psychiatric condition	70 (26.4%) including: Depression: 31 (11.7%) Schizophrenia: 18 (6.8%) Affective Disorder 10 (3.8%) Psychotic condition 8 (3%) Neurosis 3 (1.1%)

Table 1. Characteristics of participants

Procedure

The study was approved by the University ethics committee (Appendix K), and by the States of Jersey, Health and Social Services ethics committee (Appendix J). The consent process and accompanying documentation (Appendices A to G) was designed using guidance from the Mental Capacity Act (2005) and the National Research Ethics Service (NRES) (http://www.nres.nhs.uk/). The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

Researchers completed two surveys for each participant in face-to-face meetings with a proxy informant. Informants were mainly either family members or key workers within a supporting organisation. Informants were judged to be in a good position to provide information about the participant if they had a minimum of regular weekly contact and had known the participant for at least one year. All data were collected over a period of 12 months. There was no missing data.

Measures

1. Medication data

The first survey tool was adapted from the Individual Schedule of the Challenging Behaviour Survey (Alborz *et al*. 1994) and the Wessex Scale (Kushlick *et al.* 1973; Palmer & Jenkins 1982) to collect sociodemographic information and clinical characteristics including medication use. Definitions for degree of ID were taken from the UK Department for Work and Pensions Guidance (2012). This definition categorises degree of ID based on IQ score (mild: 50– 69; Moderate: 35–49; severe: 20–34; profound: less than 20) and describes typical daily living skills and support needs associated with each category. Whilst there was a reliance on proxy information, all responses were checked where possible against records stored on FACE.

Medication data collected included name of medication and corresponding dosage. For adults living in paid and congregate care settings (n = 132) data were taken directly from individual Medication Administration Records (MAR). For adults who lived independently or with family, medication use data were provided by proxy informants (n = 133).

The system for coding medication use (WHO 2014; WHOCC – ATC/DDD, 2014) has been used in other studies of medication use in individuals with ID (Scheifes *et al.* 2013; Doan *et al*. 2014). The ATC system groups medications into 14 categories according to the organs or system on which they act or their chemical, pharmacological or therapeutic characteristics (Doan *et al*. 2014). Medication was independently coded by an Intellectual Disability Nurse, with research experience, who was an independent and supplementary prescriber (v300 Qualification). Psychotropic medications were defined as medical agents for the nervous system, excluding analgesics and antiepileptics prescribed for epilepsy (Doan *et al*. 2014). Psychotropic medications included anticholinergic agents, antipsychotics, anxiolytics, hypnotics and sedatives, antidepressants, psychostimulants and antiepileptics used as mood stabilisers.

There were several cases where there were different codes for particular medicines depending on their purpose of pharmacology. In 11 cases, the research team had to return to proxy informants, or the health service database (FACE), to establish medical history and the pharmacological purpose of the medicine. Of the 68 people who were using antiepileptics, 15 did not have a diagnosis of epilepsy or history of seizures when checked against the demographic data. Further research established seven were prescribed antiepileptics as mood stabilisers so were classified in the psychotropic drug category as per previous studies (Scheifes *et al*. 2013). The other seven people were prescribed antiepileptics for absence seizures (and suspected epilepsy) or pain and were categorised under the appropriate somatic label.

For each medication, the ATC also provides a defined daily dose (DDD) which is in effect an average daily dosage for its main indication. Dosage was investigated for medication which affected the nervous system (N-coded) which included psychotropic medication. We recorded dosage against the listed DDD as below the DDD, equivalent to the DDD, or above the DDD. There were three medication entries within the nervous system category which researchers could not code due to the individual way dosage is calculated (Lithium x2) and due to brand differences (Nicotine patches x1).

The numbers of people prescribed PRN (as required) medication was very small (n = 15; 5.66%) and so we did not include this as an analysis variable (cf. Scheifes *et al*. 2013; Sheehan *et al.* 2015). The use of PRN medication has not been differentiated in previous adult population prevalence studies to compare prevalence of this figure. The PRN prevalence rate in this study of 5.66% is similar to the rate of 5% identified in the Learning Disability Census Report, 2015.

All coded medication data were then independently checked by another researcher. There were two (from 694) data entry errors, which were amended. Prevalence was then calculated for all medications. The independent coder then categorised all medication within the four digit ATC code to create a table of prevalence according to the class of the medication (Table 2).

2. Challenging behaviour data

Researchers also completed the Behavior Problems Inventory - short form [BPI-S: Appendix I] (Rojahn *et al.* 2012ab; Mascitelli *et al*. 2015) to measure challenging behaviour during the previous six months as reported by proxy informants.

Data gathered using the BPI-S were coded against the following definition (Bowring *et al.* 2017a / Chapter 2):

a) SIB: any item of self-injurious behaviour is “challenging” if either it is rated as severe and occurs at least weekly, or is rated as moderate but occurs at least daily. Any other occurrence of behaviour is not rated as challenging.
b) ADB: any item of aggressive destructive behaviour is “challenging” if either it is rated as severe and occurs at least weekly, or is rated as moderate but occurs at least daily. Any other occurrence of behaviour is not rated as challenging.
c) SB: any item of stereotyped behaviour is “challenging” if it occurs at the highest rated frequency (hourly). Any other occurrence of behaviour is not rated as challenging.
d) CB: Overall challenging behaviour is defined by the presence of a least one behaviour defined as “challenging” in the above categories.

The prevalence of challenging behaviour overall in the sample was 18.1% (95% CI: 13.94%-23.19%; n=48), self-injurious behaviour was 7.5% (95% CI: 4.94%-11.37%; n=20), aggressive and destructive behaviour 8.3% (95% CI: 5.54%-12.25%; n=22), and stereotyped behaviour 10.9% (95% CI: 7.73%-15.27%; n=29) (Bowring *et al*. 2017a / Chapter 2) .

Statistical Analysis

Data were analysed using Statistical Package for the Social Sciences Version 21 (SPSS, Inc., Chicago, Il, USA). Descriptive statistics were used to summarise the overall prevalence of medication use in the sample. We then investigated the association between challenging behaviour (total challenging behaviour, aggressive and destructive behaviour, self-injury and stereotypy) and medication using Chi Square associations, additionally estimating unadjusted Relative Risks (RR). Finally, we adjusted for other variables using multivariable Generalised Linear Models (GLM) to further explore the association between medication use and challenging behaviour.

Results

Medication prevalence

ATC section Category	**ATC four digit category**	**Number of participants (range)**	**% of participants**
N - Nervous System		138 (0-5)	52.07
	Psychotropic Medication	100 (0-5)	37.73
	Anticholinergic agents N04A	25 (0-1)	9.43
	AntiPsychotic N05A	58 (0-3)	21.89
	First generation Antipsychotic	21 (0-3)	7.92
	Second generation Antipsychotic	40 (0-1)	15.09
	Drugs for mania and hypomania Anti-psychotic	5 (0-1)	1.89
	Anxiolytics N05B	11 (0-1)	4.15
	Hypnotics and sedatives N05C	17 (0-1)	6.42
	AntiDepressants N06A	46 (0-2)	17.36
	SSRI AntiDepressants	34 (0-2)	12.83
	Tricyclic Antidepressants	5 (0-1)	1.89
	Other Antidepressants	9 (0-1)	3.40
	Psychostimulants N06B	1 (0-1)	0.38
	Antiepileptic's as Mood stabilisers N03A	7 (0-1)	2.64
	Analgesia N02A/B/C	14 (0-2)	5.28
	Antiepileptics for nerve pain N03A	3 (0-1)	1.13
	Antiepileptics for epilepsy N03A	57 (0-4)	21.51
	Dopaminergic agents N04B	2 (0-2)	0.75
	Anti-dementia drugs N06D	3 (0-1)	1.13
	Drugs used in Nicotine dependence N07B	1 (0-1)	0.38
A - Alimentary tract and metabolism		83 (0-5)	31.32
B- Blood and blood forming organs		26 (0-3)	9.81
C- Cardiovascular system		40 (0-4)	15.09
D - Dermatologicals		16 (0-2)	6.04
G - Genito-urinary system and sex hormones		30 (0-2)	11.32
H - Systemic hormonal preparations		24 (0-2)	9.06
J - Antiinfectives for systemic use		16 (0-1)	6.04
L - Antineoplastic and immunomodulating agents		2 (0-1)	0.75
M - Musculo-skeletal system		20 (0-2)	7.55
R - Respiratory System		24 (0-4)	9.06
S - Sensory organs		5 (0-1)	1.89
V - Various		6 (0-1)	2.26
	Total medication use	187 (0-14)	70.6

Table 2.The prevalence of medication use by ATC category.

Table 2 shows the prevalence of medication use within this sample. A total of 70.57% (n = 187) of adults with ID were prescribed at least one medication (mean = 2.62; range 0–14). Under the ATC system, the largest group of medications used were those coded to treat the nervous system used by 52.07% (n = 138), followed by those for alimentary tract and metabolism used by 31.32% (n = 83), followed by drugs for the cardiovascular system used by 15.69% (n = 40).

Within the total sample 37.73% (n = 100; mean = 0.68; range 0–5) used a psychotropic medication. The largest group of psychotropic medications used were antipsychotic medications used by 21.89% (n = 58; mean = 0.27; range 0–3). Most commonly used were second generation (atypical) antipsychotics used by 15.09% (n = 40). Of these, the most common medications were Risperidone (n = 16) and Olanzapine (n = 13). Of the first generation (typical) antipsychotics used by 7.92% (n = 21), the most common drug used was Haloperidol (n = 10). The second largest group of psychotropic medications was antidepressants used by 17.38% (n = 46; mean number = 0.18; range 0–2). The majority of these were selective serotonin reuptake inhibitors (SSRI) antidepressants used by 12.83% (n = 34). The most common selective serotonin reuptake inhibitors drugs used were Citalopram (n = 10), Paroxetine (n = 7) and Fluoxetine (n = 6).

Dosage and polypharmacy

Nearly one-third of participants who were prescribed medication for the nervous system were prescribed at a level above the DDD: 30.43% (n = 42) used at least one medication above the DDD (35 people took one medication above DDD, 6 people two medications above DDD, 1 person three medications above DDD).

Among those prescribed medication for the nervous system (n = 138), 41.31% were prescribed just one medication, while 58.69% were prescribed 2+ medications (mean = 3.20; range 2–5). Polypharmacy was also common with psychotropic medication. Among those prescribed psychotropic medication (n = 100), 51% were prescribed just one medication, while 49% were prescribed 2+ medications (mean = 3.69; range 2–5).

Bivariate Analysis of the challenging behaviour-psychotropic medication association

	Psychotropic Medication	Antipsychotic Medication	Antidepressant Medication
Challenging Behaviour (%):	56.3	39.6	18.8
No Challenging behaviour (%):	33.6	18	17.1
Chi Square:	$\chi^2(1)=8.55,p=.003$	$\chi^2(1)=10.74,p=.001$	$\chi^2(1)=0.08,p=.778$
Aggressive Destructive Behaviour (%):	63.6	36.4	27.3
No Aggressive Destructive Behaviour (%):	35.4	20.6	16.5
Chi Square:	$\chi^2(1)=6.85,p=.009$	$\chi^2(1)=2.94, p=.086$	$\chi^2(1)=1.64,p=.200$
Self-injurious Behaviour (%):	70	50	25
No Self-injurious Behaviour (%):	35.1	19.6	16.7
Chi Square:	$\chi^2(1)=9.58,p=.002$	$\chi^2(1)=10.00,p=.002$	$\chi^2(1)=0.88,p=.348$
Stereotypical Behaviour (%):	48.3	37.9	6.9
No Stereotypical Behaviour (%):	36.4	19.9	18.6
Chi Square:	$\chi^2(1)=1.54,p=.215$	$\chi^2(1)=4.90,p=.027$	$\chi^2(1)=2.48,p=.115$

Table 3. Chi square analysis of the association between challenging behaviour and medication use.

Chi-square tests were used to explore the association between challenging behaviour (total challenging behaviour, aggressive and destructive behaviour, self-injury and stereotypy) and medication use. Table 3 summarises these associations by detailing the percentage in the challenging behaviour and no challenging behaviour groups prescribed medication. Where associations were statistically significant at $P < 0.05$, we supplemented the chi-square results with a Relative Risk (RR) described below.

Adults with challenging behaviour were nearly twice as likely to be prescribed psychotropic medication compared with adults who did not present challenging behaviour (RR = 1.921, 95% CI: 1.328 to 2.781). Similarly, adults who displayed aggressive and destructive behaviour were nearly two times more likely to have been prescribed psychotropic medication (RR = 1.891; 95% CI: 1.207 to 2.965). The adults with self-injurious behaviour were more than two and a half times as likely to have psychotropic medications prescribed (RR = 2.606; 95% CI =1.741 to 3.902). There was no significant association between stereotyped behaviour and psychotropic medication use.

Adults with challenging behaviour were nearly three times as likely to have been prescribed antipsychotic medication compared with adults who did not present challenging behaviour (RR = 2.99; 95% CI: 1.524 to 5.869). Similarly, adults with stereotyped behaviour were nearly two and a half times as likely to use antipsychotic medication (RR = 2.457; 95% CI: 1.087 to 5.553). Adults with self-injurious behaviour were more than four times as likely to use antipsychotic medication (RR = 4.104; 95% CI: 1.617 to 10.418). There was no association between aggressive destructive behaviour and antipsychotic drug use.

There was no association between antidepressant medication use and any topography of challenging behaviour.

Multivariate analysis of the challenging behaviour-psychotropic medication association

In the final analyses, we wanted to explore whether the associations between challenging behaviour and medication use remained after accounting for potential correlates of medication use. To identify correlates, we first ran a simple generalised linear model (GLM) to obtain an unadjusted RR between the potential correlate (socio-demographic and other clinical characteristics) and the use of medication variables. Variables considered were largely those identified in previous studies such as psychiatric diagnosis, age, gender, type of residence (living in paid/congregate care vs. other), degree of ID (severe/ profound vs. mild/moderate), low communication skills (non-verbal or no clear speech and limited receptive understanding) and sensory impairments (sight or hearing impairment). All correlates significantly associated with medication use were then fitted into a multivariable GLM to examine all potentially relevant correlates alongside challenging behaviour.

GLMs were used to explore the association with the number of psychotropic medications used (0, 1, 2, 3+) fitted to follow a Poisson distribution with robust standard errors (Knoll *et al.* 2012). For a number of antipsychotic medications (defined as 0 and 1+), we fitted a logistic GLM. Results are presented in Tables 4 and 5.

Psychotropic medication	
	Unadjusted RR (95%CI; p=)
Challenging behaviour (n=48)	1.921 (1.328 to 2.781; p=.001)
Psychiatric disorder (n=70)	4.22 (3.007 to 5.92; p<.001)
Male gender (n=134)	1.312 (.91 to 1.892; p=.145)
Paid / congregate care (n=132)	2.015 (1.378 to 2.946; p<.001)
Severe / profound ID (n=58)	1.475 (1.009 to 2.155; p=.045)
Age (n=265)	1.034 (1.025 to 1.044; p<.001)
Sensory impairment (n=38)	1.134 (.696 to 1.848; p=.615)
Low communication skills (n=33)	.984 (.581 to 1.668; p=.953)
Antipsychotic medication	
	Unadjusted RR (95%CI; p=)
Challenging behaviour (n=48)	2.99 (1.524 to 5.869; p=.001)
Psychiatric disorder (n=70)	7.478 (3.945 to 14.174; p<.001)
Male gender (n=134)	2.42 (1.311 to 4.466; p=.005)
Paid / congregate care (n=132)	2.516 (1.363 to 4.644; p=.003)
Severe / profound ID (n=58)	2.099 (1.096 to 4.019; p=.025)
Age (n=265)	1.05 (1.03 to 1.071; p<.001)
Sensory impairment (n=38)	1.127 (.501 to 2.539; p=.772)
Low communication skills (n=33)	.956 (.392 to 2.328; p=.920)

Table 4. Association of psychotropic and antipsychotic medication use with participant sociodemographic and clinical characteristics (Unadjusted RR).

Psychotropic medication	
	Adjusted RR (95%CI; p=)
Challenging behaviour (n=48)	1.565 (1.074 to 2.282; p=.02)
Psychiatric disorder (n=70)	3.725 (2.68 to 5.178; p<.001)
Paid / congregate care (n=132)	1.542 (1.082 to 2.196; p=.016)
Severe / profound ID (n=58)	.926 (.627 to 1.367; p=.699)
Age (n=265)	1.023 (1.013 to 1.034; p<.001)
Antipsychotic medication	
	Adjusted RR (95%CI; p=)
Challenging behaviour (n=48)	2.968 (1.131 to 7.79; p=.027)
Psychiatric disorder (n=70)	9.124 (4.151 to 20.058; p<.001)
Male gender (n=134)	3.35 (1.573 to 7.134; p=.002)
Paid / congregate care (n=132)	1.096 (.774 to 4.698; p=.161)
Severe / profound ID (n=58)	1.131 (.427 to 2.998; p=.804)
Age (n=265)	1.043 (1.018 to 1.069; p=.001)

Table 5. Association of psychotropic and antipsychotic medication use with participant sociodemographic and clinical characteristics (Adjusted RR).

Results from GLM Poisson regression models showed that those with a psychiatric diagnosis had a 4.22 RR (95% CI 3.007 to 5.92; P < 0.001) of being prescribed psychotropic medication (Table 4). Those living in paid or congregate care had a 2.015 RR (95% CI 1.378 to 2.946; P < 0.001); those who presented challenging behaviour a 1.921 RR (95% CI 1.328 to 2.781; P < 0.001); adults with a severe profound ID a 1.475 RR (95% CI 1.009 to 2.155; P = 0.045); and (older) age gave a 1.034 RR (95% CI 1.025 to 1.044; P < 0.001). There were no significant associations between gender, sensory impairment or low communication skills and the use of psychotropic medication. When all significantly associated variables were entered in the GLM model together (Table 5), severe-profound ID was no longer significantly associated with psychotropic use. Significant correlates remaining included psychiatric disorder (RR = 3.725; 95% CI 2.68 to 5.178; P < 0.001), challenging behaviour (RR = 1.565; 95% CI 1.074 to 2.282; P = 0.02), living in paid/congregate care (RR = 1.542; 95% CI 1.082 to 2.196; P = 0.016) and (older) age (RR = 1.023; 95% CI 1.013 to 1.034; P < 0.001).

Using GLM loglink regression models, we found that those with a psychiatric diagnosis had a 7.478 RR (95% CI 3.945 to 14.174; P < 0.001) of using antipsychotic medication (Table 4). Those who presented with challenging behaviour had a 2.99 RR (95% CI 1.524 to 5.869; P = 0.001); those living in paid/congregate care a 2.516 RR (95% CI 1.363 to 4.644; P = 0.003); males had a 2.42 RR (95% CI 1.311 to 4.466; P = 0.005); those with a severe/profound ID a 2.099 RR (95% CI 1.096 to 4.019; P = 0.025); and (older) age a 1.05 RR (95% CI 1.03 to 1.071; P < 0.001). There was no significant association between sensory impairments and low communication skills and antipsychotic medication use. When all significant correlates were entered into the model together (Table 5), living in paid/congregate care and severe/profound ID were no longer significant. Significant correlates remaining were psychiatric disorder (RR = 9.124; 95% CI 4.151 to 20.058; P < 0.001), male gender (RR = 3.35; 95% CI 1.573 to 7.134; P = 0.002), challenging behaviour (RR = 2.968; 95% CI 1.131 to 7.79; P = 0.027) and (older) age (RR = 1.043; 95% CI 1.018 to 1.069; P = 0.001).

Discussion

Among the total administrative population of adults with ID in Jersey, nearly 4 in 10 were in receipt of at least one psychotropic medication (37.73%, n = 100) and 30.43%, (n = 42) were prescribed a medication which acts on the nervous system above the indicated daily dose. Nearly half of all adults prescribed psychotropic medications (49%, n = 49) were in receipt of more than one of these medications. Thus, the use of psychotropic medication, at high doses and polypharmacy were common supporting previous evidence (Deb *et al.* 2014; Henderson *et al*. 2015; Sheehan *et al.* 2015). The most prevalent group of medications was antipsychotics, prescribed to 21.89% of people. This confirms the preference for this type of medication by prescribers as seen in other studies (Holden & Gitlesen, 2004; Deb & Unwin, 2007; Matson & Neal, 2009; Singh &Matson, 2009). Second generation antipsychotics were used by 15.09% of the sample which confirms a shift in prescribing patterns to second generation antipsychotics and SSRIs (Spreat *et al.* 2004; Matson & Neal, 2009; Paton *et al.* 2011).

The prevalence of psychotropic drug use is lower in our sample than those reported from other recent studies in the UK (e.g. Henderson *et al.* 2015, 49.1%; Sheehan *et al*. 2015, 49%). There are a number of potential reasons for this. First, one strength of this population study was that it did not recruit from a particular clinical route such as participants in contact with GPs and psychiatrists (e.g. Henderson *et al.* 2015; Sheehan *et al*. 2015). Sheehan *et al.* (2015) indicate they may have over-estimated prevalence of prescribing due to difficulties identifying adults with mild ID from GP records. The total population ascertainment process in this study used multiple routes. There may be potentially lower prevalence estimates in studies that consider total population samples and not just primary care records or records from specialised challenging behaviour, residential or hospital services. In a county in Norway, adults with ID known to services (n = 300) and living in the community, had a similar prevalence of psychotropic prescribing (37.4%) to the current study (Holden & Gitlesen, 2004).

Second, our total population study did not recruit from one specific clinical setting like other studies with high prevalence rates (e.g. Griffiths *et al.* 2012, 72%; Deb *et al*. 2014, 89%) but from multiple routes. We found prevalence of antipsychotics by residence was only 11% for those residing in family homes, 21.4% in independent living and much higher at 29.5% in paid/congregate care. Studies that have considered differing prescribing patterns by including community samples may lead to lower prevalence estimates.

Third, previous studies have identified regional variations in prevalence rates between districts of origins in the UK (Kiernan *et al.* 1995). This has been explained by the fact that prescribing professionals, practices and samples will vary by region. There appears to be less use of certain medications in Jersey. Sheehan *et al.* (2015) reported a 21% prevalence of antipsychotics and 20% prevalence of antidepressants which was similar to the present sample (21.89% and 17.36%), but a higher prevalence of mood stabilisers (20%) and anxiolytics/hypnotics (22%) compared with the present sample (2.64% and 10.57%). The Jersey General Hospital Formulary (States of Jersey, 2016) lists medications licenced to be prescribed in Jersey. This may detail a slightly different set of medications to other authorities/countries and identifies some medications that GPs cannot prescribe.

In Jersey, all adults with ID and challenging behaviour are open to the ID psychiatrist. Whilst individuals with ID and challenging behaviour would be open to the ID psychiatrist, other adults with ID could be reviewed by other members of the psychiatry department or be in receipt of medication from GP's. Some evidence has suggested a reduced level of prescribing from psychiatrists compared with GPs (Holden & Gitlesen, 2004). We found that 39.7% of adults with ID in receipt of antipsychotic medication did not have a psychiatric disorder. This rate is lower than that reported in other recent studies (50–71%: Tsiouris, 2010, Paton et al. 2011; Marston et al. 2014; Sheehan et al. 2015). The presence of a dedicated ID psychiatrist in Jersey may have contributed to lower rates of prescribing. Further investigations are required into regional variations and what influences prescribing patterns of individual medications at a prescriber level.

Our data also suggested that psychotropic medication prescribed in the absence of a psychiatric diagnosis may be related to the presence of challenging behaviour. Ascertainment of the presence of challenging behaviour was a strength of the current study through the BPI-S. Our data extended previous findings (Brylewski & Duggan 2004; Tsiouris, 2010; Henderson *et al*. 2015; Sheehan *et al.* 2015) by indicating different patterns of association with specific topographies of challenging behaviour. Psychotropic medication use was associated with aggressive/destructive behaviour and self-injurious behaviour, but not stereotyped behaviour. Antipsychotic medication use was associated with self-injurious behaviour and stereotyped behaviour, but not aggressive/destructive behaviour. Adults with SIB in particular may be a priority for psychosocial interventions and medication reviews. It is of interest that antipsychotic use was associated with behaviours that could be considered inner-directed (self-injury and stereotypy), but not outward-directed such as aggression/destruction. In the presence of aggression/destruction, the relative risk of using hypnotics/sedatives was over 200% and 700% for using antiepileptics as mood stabilisers. Mood stabilisers for aggression have been documented in other studies (Deb *et al.* 2014;

Wilner, 2014: Tsiouris *et al.* 2015). Overall, our data indicate that differences in prescribing patterns may be associated with specific challenging behaviours, or the features associated with those behaviours which requires further investigation.

Factors other than challenging behaviour and psychiatric diagnosis were also independently associated with medication use. Psychotropic medication use was additionally associated with living in paid/congregate care and increased age. Antipsychotic medication was similarly associated with increased age and also male gender. Associations between psychotropic medication use, older age and type of residence have been seen consistently in other studies (Aman *et al.* 1995; Kiernan *et al.* 1995; Singh *et al.* 1997; Robertson *et al*. 2000; Holden & Gitlesen, 2004; Sheehan *et al.* 2015). The increased likelihood of receiving antipsychotic medication for males compared with females has also been reported in other studies and requires further exploration to consider why this is (McGillivray & McCabe, 2006; Delafon *et al*. 2013; Doan *et al.* 2014).

A limitation of the present study is that findings apply only to the administratively defined ID population in Jersey while there may also be adults with ID (IQ < 70) not known to services who were not included. However, findings from this study are likely useful in practice because specialised support (such as for medication reviews) might be best planned on the basis of a population of people with ID already known to services. The sample size was also relatively small compared with other recent studies. A second limitation was the reliance on proxy informants to report medication use for those living in family or independent settings (133 participants) where there is a possibility of misreporting as these informants are not clinically trained. However, potential inaccuracy was limited as proxy informants often showed researchers the medication with listed name and dosage; where they were unsure they made further enquiries and researchers contacted them again. Follow up checks were also made on the FACE database as initial assessments, care plans and nursing plans listed on FACE usually contained information on medication use. PRN medication use was rare, but future studies with larger samples could also consider separate analysis of these medications. Within Jersey H&SS, and approved provider residential provisions, PRN medication can only be administered by Learning Disability Nurses. Given that in other settings and jurisdictions, PRN may be given by untrained staff or carers without documentation and monitoring, it will be a crucial variable to consider in future studies.

Implications for policy and practice

Despite the lower prevalence in this sample, prescribing levels of psychotropic medication are still too high and often related to challenging behaviour with no evidence this practice is effective (Matson & Neal, 2009). Studies on withdrawing medication suggest many adults with ID can do so successfully (Ahmed *et al.* 2000). Health organisations should complete audits to ascertain psychotropic prescribing levels and identify adults requiring a psychiatric review of their medication. The involvement of specialist prescribers, rather than GPs, is essential as there is evidence prescribing rates are lower where psychiatrists lead prescribing (Holden & Gitlesen, 2004).

Although requiring future replication, we found that different topographies of behaviour related to different patterns of prescribing, with those with SIB being a particularly high risk group. Efforts should be made to reduce prescribing in high risk populations by prioritising them for medication reviews (RCP, 2016) and alternative psychosocial interventions. We also found that general medication use is high in adults with ID (for example, 31.32% were in receipt of medication for the alimentary tract and metabolism) and future research needs to investigate the high prevalence of all types of medication prescribed and whether these are indicated by an underlying health need.

CHAPTER 4

Towards data-based clinical decision making for adults with challenging behaviour using the Behavior Problems Inventory – Short Form (BPI-S)

The BPI-S (Rojahn *et al*. 2012) had been used in chapter 2 to classify the prevalence and severity of challenging behaviour in the total population of adults with ID in Jersey. The data set of 265 participants was utilised to further develop the BPI-S measure for use in research and clinical practice. In this chapter, population norms are reported for the BPI-S and clinically significant cut-off scores and reliable change scores presented. The chapter was intended to be a very practical with case examples provided to support services and practitioners utilise the useful statistics on population norms, statistically significant and clinically significant change scores provided. Services currently lack such a tool to support the measurement of meaningful behaviour change and this chapter aimed to address this issue. This chapter was also completed with the intention of providing a measure of meaningful behaviour change required for the evaluation of a PBS service outcome data described in chapter 5.

Abstract

Background. The Behavior Problems Inventory – Short Form (BPI-S) is a shorter version of the Behavior Problems Inventory - 01 (BPI-01). In this paper, BPI-S population norms are reported from a total administrative population of adults with Intellectual Disability (ID). To facilitate the use of the BPI-S in clinical services to assess behaviour change, this paper describes how to use BPI-S clinically significant and reliable change scores.

Method. Data were gathered on 265 adults with ID known to services. Proxy informants completed the BPI-S on challenging behaviours presented during the previous 6 months. Clinically significant cut-off values and reliable change scores were calculated using the Jacobson and Truax (1991) method.

Results. BPI-S clinical reference data are presented to provide benchmarks for individual and group comparisons regarding challenging behaviour. Examples demonstrate how to use clinical norms to determine change.

Conclusions. Behaviour change is a major goal of researchers and practitioners. Data from the present study can make the BPI-S a valuable tool for determining change in challenging behaviour following service input or intervention. Whilst well used in research, the BPI-S may be less extensively used in practice. This present study provides data to enable researchers and practitioners to use the BPI-S more widely in assessing clinical outcomes, such as intervention research and service evaluation.

Keywords challenging behaviour, intellectual disability, Behavior Problems Inventory, normative data, reliable change.

Introduction

Recent population studies reveal a consistently high prevalence of challenging behaviour in individuals with intellectual disabilities (ID): Prevalence estimates range from 18.1% (Bowring *et al.* 2017a / Chapter 2) to 22.5% (Jones *et al*. 2008). Given time and resource pressures, assessment of challenging behaviour in this population is often undertaken using proxy reported behaviour rating scales instead of direct behaviour observation. Behaviour rating scales, using data from individuals who know the person well, are useful for researchers and for services tasked with developing intervention approaches and monitoring behaviour change.

The Behaviour Problems Inventory – short form (BPI-S: Appendix I) is one such instrument which includes assessment of three of the most common challenging behaviour topographies in individuals with ID (Rojahn *et al.* 2012a). The BPI-S is a shorter and more 'user-friendly version' of the Behaviour Problems Inventory – 01 (Rojahn *et al.* 2001) which has been used in numerous studies and has been reported to have acceptable to very good psychometric properties (Sturmey *et al*. 1993; Sturmey *et al*. 1995; Sturmey, 2001; Rojahn *et al*. 2001). The BPI-S is a standardised and reliable rating scale, with evidence of acceptable validity to assess challenging behaviour in individuals with ID (Mascitelli *et al*. 2015; Rojahn *et al.* 2012a, b). It has been demonstrated to have adequate to good internal consistency (Mascitelli *et al*. 2015; Rojahn *et al.* 2012a, b), inter-rater agreement and test-retest reliability (Mascitelli *et al*. 2015), strong evidence for confirmatory and discriminant validity (Rojahn *et al.* 2012a, b); and confirmatory factor analysis has validated the three BPI-S subscales (Mascitelli *et al.* 2015).

As the BPI-S is utilised in clinical practice and research it is essential to develop criteria to allow users to appropriately interpret BPI-S results obtained from individual and group assessments, especially over time (i.e., in the context of outcome assessment/behaviour change). Population norms are useful to establish how an individual's behaviour problem scores compares to the general adult ID population. Population norms also provide a benchmark to assist comparison between studies, to identify individuals requiring support / intervention, and allow the estimation of numbers across populations with likely challenging behaviour. Population norms may be useful to challenging behaviour services at screening, when evaluating case input or to prioritise case allocation. Without points of comparison, interpreting the meaning of psychological assessments, such as the BPI-S, is difficult (Cicchetti, 1994; APA, 1995).

Given the significant health and quality of life impact of challenging behaviour on individuals with ID and their carers (Emerson *et al*. 2001; Joyce *et al*. 2001; Hastings & Brown, 2002; Cooper *et al*. 2009), considerable clinical and financial investment is made in interventions for challenging behaviour and also specialist challenging behaviour services (McGill & Poynter, 2012). For challenging behaviour services, outcome assessments are needed that can be used in regular clinical practice to show whether the amount of behaviour change is meaningful and whether services are effective or not. Normative data can be further used in the generation of criteria to assess clinically significant change – a measure that is becoming increasingly more important in practice (Aardoom *et al*. 2012). Clinically significant change is demonstrated when a person moves from outside the range of the “dysfunctional” population to within the range of the “functional” population (Jacobson & Truax, 1991).

Although the benefits of informant-based measures are clear, reports from proxy informants based on recollections of behavioural issues alongside personal judgements, could lead to erroneous hypotheses, so practitioners should supplement these tools with additional direct measures to establish robust conclusions.

The current paper describes how to use the BPI-S to assess individual behaviour change and services’ effectiveness. Examples are drawn from clinical practice to illustrate how to use the normative data, together with clinical and reliable change criteria for the BPI-S.

Source of data

Data were gathered from 265 persons ≥ 18 years of age administratively defined as having ID (i.e., who were receiving, or had received, support from services in Jersey). Participants were identified from multiple sources including the Health and Social Services (H&SS) administrative database, in Jersey, FACE (Functional Analysis of Care Environments, http://www.face.eu.com). FACE is a database used by the local community multi-disciplinary ID service which includes social work, occupational therapy, community nursing, psychiatry and positive behavioural support service. Records were cross-referenced with current Education Department Record of Needs, and records of individuals maintained by local service providers from the voluntary sector and employment support services. The population ascertainment process and more detail on the procedure is provided in a previous paper (Bowring *et al*. 2017a / Chapter 2).

The ascertainment process identified 311 potential participants. Surveys were completed with 265 participants which is equivalent to 97% of eligible and traceable participants (*n*=274; 9 declined consent) or 85% of eligible people (*n*=311; 11 were traced but did not reciprocate contact, and we were unable to trace 26). Thus, the dataset is a robust representation of the Jersey population of adults in receipt of ID services. This sample meets validity criteria for normative data being based on a clearly defined and well represented population sample (Hopman *et al*. 2000). Informed consent was obtained from 162 adults. For 103 adults who did not have capacity to provide independent consent, consultees gave consent For information on the consent process and documentation see appendices A to G. Full demographic information about the sample can be found in Bowring *et al*. (2017a) / Chapter 2.

The research was approved by the University's School of Psychology research ethics and governance committee (Appendix K), and by the States of Jersey, Health and Social Services ethics committee (Appendix J).

Researchers gathered BPI-S data for each participant in face-to-face meetings with a proxy informant. Informants were either family members or key workers within a support organisation. Informants were selected if they had a minimum of regular weekly contact and had known the participant for at least one year. All data were collected over a period of 12 months (2013-2014). There were no missing data, which is a significant strength of the study, particularly given levels of missing data in previous studies (Rojahn *et al.* 2012a, b; Mascitelli *et al*. 2015).

The Behavior Problems Inventory - Short Form

The BPI-S (Appendix I) comprises 30 items arranged in 3 subscales: the Self-injurious Behaviour (SIB) subscale contains 8 items, the Aggressive Destructive Behaviour (ADB) sub-scale 10 items, and the Stereotyped Behaviour (SB) sub-scale 12 items. The BPI-S measures challenging behaviours present during the previous six months (Rojahn *et al*. 2012a). The BPI-S has two Likert-type rating scales per item – a five-point frequency scale (never = 0; monthly = 1; weekly = 2; Daily = 3; Hourly = 4) and a three-point severity scale (mild = 1; Moderate = 2; Severe = 3). A behaviour rated as mild, in terms of severity, is defined as behaviour that does not cause significant damage to the individual or others, such as reddening of the skin, and any property damage that does not require repair or replacement. A moderate severity behaviour is one that causes damage to the individual or others such as bruising or causes damage to the environment requiring repair. A severe impact behaviour is one that inflicts moderate to severe damage to the individual or others, requiring medical intervention, or causes damage to items which are beyond repair. Frequency and severity of behaviour are measured for the SIB and ADB subscales, and frequency alone for the SB subscale. For each item, a score is generated by multiplying the frequency and severity scores and the sum of these product scores generates a subscale score. The sum of the three subscales gives a BPI-S total score.

In the present sample, Cronbach's alpha (Cronbach, 1951) for the total BPI-S frequency and severity scales was .891 and .773 respectively (See Bowring *et al*. 2017a / Chapter 2). Table 1 compares BPI-S alpha scores for the current sample with previous research by Rojahn *et al.* (2012a, b) and Mascitelli *et al.* (2015). Internal consistency appears to be consistently lower in the SIB subscale in all three studies indicating it may be the least robust of the three subscales (.681 and .627 for the SIB frequency and severity scale respectively in this sample). The comparatively lower α-coefficients for the SIB subscale may be related to either lower frequencies of these behavioural topographies or ambiguity of the SIB construct (Rojahn *et al.* 2012b; Mascitelli *et al.* 2015).

	Mascitell *et al.* 2015				**Rojahn *et al.* 2012b**		**Bowring *et al.* 2017a**	
	Minnesota sample		**Welsh Sample**		**Mixed location**		**Jersey**	
	Freq.	*Sev.*	*Freq.*	*Sev.*	*Freq.*	*Sev.*	*Freq.*	*Sev.*
SIB	.75	.72	.44	.45	.70	.68	.68	.63
ADB	.78	.85	.80	.89	.89	.89	.79	.79
SB	.86		.75		.88		.87	

Table 1. Internal Consistency of the BPI-S subscales (Cronbach's α) by study

BPI-S population norms

To establish BPI-S norms the prevalence of each individual item within the sample was calculated (*n*, %), and the frequency and severity score summarised (%) (see Table 1). The overall prevalence of participants presenting at least one item behaviour within each subscale was calculated (*n*, %), alongside the median, mean, standard deviation, range and variance of the BPI-S subscale and total scores (see Table 2). Mean and standard deviation scores for BPI-S subscales and totals by age and gender were determined. Given median age in this sample was 40.44 and mean age was 41.44 we separated participants into the 18-40 age group (*n*=132) and the 41 and above age group (*n*=133). There were also similar participant numbers in the groups separated by gender (Male: *n*=134; Female: *n*=131).

Table 2 lists item endorsement from the total population sample. The highest prevalence rates were in the ADB subscale (41.13%) with item endorsements from item #12 biting others of 2.26% to 23.77% item #16 verbal abuse to others. The second highest prevalence rates were in the SB subscale, ranging from item #28 bizarre body postures 4.53% to item #24 yelling and screaming with an endorsement rate of 16.6%. The SIB subscale had the lowest prevalence rates ranging from 1.13% endorsement of item #6 inserting objects to 10.94% of item #4 self-scratching.

Subscale & Items					**Frequency of occurrence (%)**				**Severity of the problem (%)**		
Self-Injurious Behaviour		Never a problem (n)	Problem (n)	Problem (%)	Monthly	Weekly	Daily	Hourly	Mild	Moderate	Severe
1	Self-biting	250	15	5.66	1.89	3.02	0.75	0	3.02	2.64	0
2	Head hitting	242	23	8.68	3.40	2.64	2.64	0	4.53	3.02	1.13
3	Body hitting	248	17	6.42	2.26	1.89	2.26	0	3.77	2.26	0.38
4	Self-scratching	236	29	10.94	4.53	3.02	2.64	0.75	4.15	4.91	1.89
5	Pica	256	9	3.4	1.89	0.38	1.13	0	1.51	1.13	0.75
6	Inserting objects	262	3	1.13	0.38	0.38	0.38	0	0.75	0.38	0
7	Hair pulling	256	9	3.4	1.13	0.38	1.89	0	0.38	1.89	1.13
8	Teeth grinding	248	17	6.42	1.51	0.38	2.64	1.89	4.53	0.75	1.13
Aggressive/Destructive Behaviour											
9	Hitting others	211	54	20.38	15.09	3.77	1.51	0	9.81	9.43	1.13
10	Kicking others	246	19	7.17	6.04	0.75	0.38	0	3.40	3.02	0.75
11	Pushing others	223	42	15.85	13.21	1.13	1.51	0	10.94	4.15	0.75
12	Biting others	259	6	2.26	2.26	0	0	0	0.75	1.13	0.38
13	Grabbing and Pulling others	230	35	13.21	8.30	2.26	2.64	0	7.55	4.91	0.75
14	Scratching others	255	10	3.77	2.26	0	1.51	0	1.51	2.26	0
15	Pinching others	252	13	4.91	3.02	1.51	0.38	0	2.64	1.89	0.38
16	Verbally abusive with others	202	63	23.77	12.83	6.79	3.40	0.75	15.85	6.42	1.51
17	Destroying things	217	48	18.11	11.70	5.28	0.75	0.38	8.30	8.68	1.13
18	Bullying - being mean or cruel	244	21	7.92	3.77	1.89	2.26	0	4.91	2.64	0.38
Stereotyped Behaviour											

19	Rocking, repetitive body movements	227	38	14.34	2.26	3.02	5.66	3.40
20	Sniffing objects, own body	252	13	4.91	1.13	0.75	2.26	0.75
21	Waving or shaking arms	235	30	11.32	2.26	2.26	4.15	2.64
22	Manipulating objects	240	25	9.43	2.26	0.38	5.28	1.51
23	Repetitive hand and/or finger movements	230	35	13.21	1.13	2.26	4.15	5.66
24	Yelling and screaming	221	44	16.6	5.28	4.53	4.15	2.64
25	Pacing, jumping, bouncing, running	229	36	13.58	4.15	3.02	3.77	2.64
26	Rubbing self	239	26	9.81	1.89	1.51	4.15	2.26
27	Gazing at hands or objects	235	30	11.32	2.26	3.02	3.77	2.26
28	Bizarre body postures	253	12	4.53	0.75	0.75	1.89	1.13
29	Clapping hands	250	15	5.66	0.75	1.89	1.89	1.13
30	Grimacing	235	30	11.32	1.89	2.64	5.28	1.51

Table 2. Endorsement of BPI-S items in the Jersey adult administrative ID population (n, %)

Table 3 lists the descriptive BPI-S Scale statistics. Results indicate that 41.13% of participants presented at least one behaviour item listed within the ADB subscale, 37.36% presented with at least one behaviour in the SB subscale, and 24.15% for the SIB subscale. Overall, 58.49% of participants presented with behaviour leading to the endorsement of at least one item behaviour in the BPI-S. Median BPI-S scores in the three subscales were zero given the majority of participants did not present with a listed item behaviour. Mean BPI-S subscale product scores were 3.28 for SB (SD =6.588), 2.76 for ADB (SD=5.519), 1.59 for SIB (SD=4.183). The BPI-S total mean score was 7.63 (SD=12.833).

Table 3 also lists the mean scores in the BPI-S subscales by gender and age. Mean scores for males are higher than females in all subscales. Mean scores for the younger group (18-40 years) are higher in the ADB, SB and BPI-S total scale, but lower than the older group (41 years plus) in the SIB subscale.

Items	SIB	ADB	SB	BPI-S Total
Prevalence of at least one behaviour (*n*)	64	109	99	155
Prevalence of at least one behaviour (%)	24.15	41.13	37.36	58.49
Median BPI-S subscale score	0	0	0	2
Mean BPI-S subscale score (SD)[1]	1.59 (4.18)	2.76 (5.52)	3.28 (6.59)	7.63 (12.83)
Range	30	36	45	84
Min	0	0	0	0
Max	30	36	45	84
Variance	17.5	30.46	43.40	164.70
Skewness(SE)	3.87 (.150)	2.97 (.150)	2.99 (.150)	2.61 (.150)
Male mean (SD)	2.00 (5.01)	3.40 (5.30)	4.13 (7.71)	9.54 (14.55)
Female mean (SD)	1.18 (3.09)	2.10 (5.68)	2.40 (5.07)	5.67 (10.50)
18-40 years mean (SD)	1.43 (3.73)	2.80 (5.68)	3.52 (6.83)	7.74 (13.25)
41+ years (SD)	1.75 (4.60)	2.72 (5.37)	3.04 (6.36)	7.59 (12.46)

[1](SIB & AD = Sum of Freq*Sev scores; Stereo = Freqsum; BPI-S Total = Sum of SIB, AD, SB subscales)

Table 3. Descriptive BPI-S Scale statistics

How to use the normative data

As an example of how to use the normative data, a psychologist completed the BPI-S on an adult with ID. This individual scored 15 on the ADB product subscale, which when the psychologist looked at mean subscales scores on table 3 this was higher than the population norm of 2.76. The highest rated behaviour was item #9 Hitting Others where the individual was rated as displaying this weekly and severely. Looking at table 2 the psychologist noted that although 20% of adults with ID do present with this behaviour, just 3.77% display it weekly and only 1.13% at a severe level suggesting “Hitting others” may be a behaviour requiring prompt intervention support.

In another example, a regional care provider completed the BPI-S on 40 adults with ID across 17 residential settings. A prevalence rate of SIB of 37.5% was discovered which was higher than the 24.15% norm provided in table 3. Other aggressive and stereotypical behaviours were closer to the listed norms. As a result, the provider focused on SIB and ensured everyone engaging in SIB was prioritised for a functional behaviour assessment. The provider was also clear from the BPI-S item listings about the specific SIBs that required assessing and the relevant frequency and severity score at point of referral (that could be used to determine behaviour change later).

BPI-S Clinically significant change scores

At the individual level, a key question in relation to intervention is whether the person's problems have changed sufficiently that he or she might be considered no longer to "have" that problem. This is a critical issue in services, but also an area of interest to researchers. Jacobson and Truax (1991) propose three ways to operationalise clinically significant change: when someone moves from outside the range of the "dysfunctional" population (in this case, the population who meet criteria for displaying challenging behaviour) to within the range of the "functional" population (in this case, those not displaying challenging behaviour). It should be noted that the terms "functional" and "dysfunctional" are taken from the Jacobson and Truax (1991) paper and are used to describe the approach taken to operationalise this analysis. This language is incompatible with descriptors of individuals with ID and should not be utilised as a diagnostic category:

a) The level of functioning subsequent to intervention should fall outside the range of the dysfunctional population, where range is defined as extending two standard deviations beyond (in the direction of functionality) the mean of that population.
b) The level of functioning subsequent to intervention should fall within the range of the functional or normal population, where range is defined as within two standard deviations of that population.
c) The level of functioning subsequent to intervention places that client closer to the mean of the functional population than it does to the mean of the dysfunctional population.

When population norms are available, there is potential overlap between the scores of the functional and dysfunctional populations or there are unequal distributions, then Jacobson and Truax (1991) recommend using method c (above). Using method c, clinical change would be established if following treatment for challenging behaviour the BPI-S score falls closer to the mean of the functional population than the dysfunctional. Jacobson and Truax (1991) suggest the following equation for determining a cut-off score based on two unequal distributions where S represents the standard deviation, M the mean, and 0 or 1 the non-challenging behaviour population and the challenging behaviour population:

$$C = S_0M_1 + S_1M_0 / S_0 + S_1$$

Using this formula, clinically significant cut-off points can be calculated. Such a method of determining the cut-off score allows researchers and clinicians to make a determination about within which population a given score falls. This would be useful for practitioners at initial screening to identify those that have BPI-S scores within the clinical range; or for assessing whether a particular intervention has successfully provided clinically significant change (Connell *et al*. 2007).

In a previous study (Bowring *et al.* 2017a / Chapter 2), the authors identified and differentiated between the dysfunctional population (those with defined challenging behaviour) and the functional population (those without defined challenging behaviour). Challenging behaviour was defined as such (Bowring *et al.* 2017a / Chapter 2):

a) SIB: any item of self-injurious behaviour is "challenging" if either it is rated as severe and occurs at least weekly, or is rated as moderate but occurs at least daily. Any other occurrence of behaviour is not rated as challenging.
b) ADB: any item of aggressive destructive behaviour is "challenging" if either it is rated as severe and occurs at least weekly, or is rated as moderate but occurs at least daily. Any other occurrence of behaviour is not rated as challenging.
c) SB: any item of stereotyped behaviour is "challenging" if it occurs at the highest rated frequency (hourly). Any other occurrence of behaviour is not rated as challenging.
d) CB: Overall challenging behaviour is defined by the presence of a least one behaviour defined as "challenging" in the above categories.

The overall prevalence of challenging behaviour identified in this sample was 18.1% (95% CI: 13.94%-23.19%; *n*=48), self-injurious behaviour was 7.5% (95% CI: 4.94%-11.37%; *n*=20), aggressive and destructive behaviour 8.3% (95% CI: 5.54%-12.25%; *n*=22), and stereotyped behaviour 10.9% (95% CI: 7.73%-15.27%; *n*=29) (Bowring *et al*. 2017a / Chapter 2). Table 4 shows mean BPI-S subscale and total scores for both functional (no defined challenging behaviour) and dysfunctional (defined challenging behaviour) populations.

Population with Challenging Behaviour (“Dysfunctional”; M1)							
BPI-S Scale	***N***	***Mean BPI-S (M_1)***	***Range***	***Minimum***	***Maximum***	***SD (S_1)***	***Variance***
SIB	20	13.2	24	6	30	7.04	49.54
ADB	22	16.23	30	6	36	7.93	62.95
SB	29	16.83	41	4	45	9.36	87.65
BPI-S Total	48	27.02	79	5	84	17.25	297.64
Population without Challenging Behaviour (“Functional”; M0)							
SIB	245	.64	12	0	12	1.77	3.13
ADB	243	1.54	22	0	22	3.13	9.78
SB	236	1.61	24	0	24	3.59	12.86
BPI-S Total	217	3.34	38	0	38	5.87	34.46

Table 4. BPI-S scores for the population that presents with some challenging behaviour and the population without challenging behaviour.

Table 5 shows the mean score of the CB population (M_1), the mean score of the non-CB population (M_0) and the clinically significant cut-off score. The cut-off point is the score an individual would need to cross following intervention (for challenging behaviour) to be classified as changed to a clinically significant degree.

	M_1	**M_0**	**Clinically Significant cut off point. (Method c).**
SIB	13.2	.64	1.88
ADB	16.23	1.54	5.69
SB	16.83	1.61	5.66
BPI-S TOTAL	27.02	3.34	9.35

(M_1=mean of population with CB; M_0=mean of population without CB)

Table 5. Clinically significant BPI-S cut off point.

How to use clinically significant change scores

As an example, an adult who attends a local authority Day Service engages in challenging behaviour and the BPI-S ADB subscale product score is 16. If a function-based intervention was implemented for the specific challenging behaviours, a BPI-S ADB post intervention score of 5.69 or below (using Table 5) would be needed for that individual to be deemed as falling within the range of the non-challenging behaviour population.

The cut-off scores can also be used by services to identify to which population an individual belongs. For example, a multi-disciplinary ID service screening all adults referred for challenging behaviour using the BPI-S. At the weekly meeting two adults are referred both of whom show some aggressive behaviour. One individual scores 12 on the BPI-S ADB subscale indicating scores within the dysfunctional (challenging behaviour) population (Table 5). The second individual scores 4 on the same subscale indicating a score within the range of the “functional” population. Using such data the service might prioritise the first adult for support.

BPI-S Reliable behaviour change scores

As well as demonstrating clinically significant change when post treatment scores fall within the range of the normative population, the approach described by Jacobson and Truax (1991) also requires evidencing that the pre-to-post test score change for an individual is statistically significant. This is because if only clinically significant change is addressed, some very small (likely not meaningful) changes could be considered important, when in fact they may not be meaningful in terms of impact on everyday life. Scores close to the clinical cut-off that drop below this level may be associated with small change, and a very high-scoring individual may change substantially, but still not drop below the clinical cut-off score.

Reliable change (RC) is the amount by which an outcome measure needs to change before we can be 95% certain that the change is not accounted for by the variability of scores in the sample and / or measurement error (Jacobson & Truax, 1991). To increase our confidence that changes in scores on the BPI-S across administrations represent real behaviour changes, a reliable change (RC) index was established. The mean score in each BPI-S subscale and BPI-S total scores and the corresponding standard error (SE) were calculated (Table 3). The formula for the SE of measurement of a difference (where SD_1 is the standard deviation of the pre-test score and, r is the reliability of the measure) is:

$$SE_{diff} = SD_1\sqrt{2\sqrt{1}} - r.$$

Change exceeding 1.96 times this SEdiff is unlikely to occur more than 5% of the time by unreliability of the measure alone. Thus, RC>1.96SEdiff. RC scores were calculated for every BPI-S subscale and total BPI-S scores in two ways. First, RC scores were calculated on the total population sample (*n*=265). This RC value will be a useful comparative figure for researchers or practitioners studying behaviour change in population samples. Second, a RC value for individuals scoring 1+ on the BPI-S (*n*=155) was calculated, thus demonstrating some challenging behaviour. This will provide a useful comparative figure for researchers or practitioners studying behaviour change in individuals / groups with some challenging behaviour, (e.g., Positive Behavioural Support (PBS) / Challenging Behaviour services).

Table 6 shows the RC scores for the frequency and severity subscales and BPI-S total scores for the total population group (n=265) and for the 1+ scorers (N=155). Given the higher mean scores and SD, the RC values for the 1+ scorers are more conservative. In this group, change in total BPI-S score of 10.37 would indicate reliable change, as would 8.35 in SB, 7.35 in SIB and 6.26 in ADB total. The RC scores from the total population sample are 5.30 for BPI-S total, 4.87 for SIB, 6.66 for SB and 4.50 for ADB.

Reliable Change Scores – total population sample (*n*=265)

BPI-S Scale	**Mean**	**Range**	**SD**	**Cronbach's Alpha**	**RC Score**
SIB Freq	.95	0-16	2.351	.681	3.68
SIB Sev	.76	0-10	1.759	.627	2.98
SIB Total	1.59	0-30	4.183	.824	4.87
ADB Freq	1.73	0-18	3.112	.792	3.97
ADB Sev	1.76	0-15	3.030	.788	3.86
ADB Total	2.76	0-36	5.519	.893	4.50
SB Freq	3.28	0-45	6.588	.867	6.66
BPI-S Total	7.63	0-84	12.833	.915	5.30
Reliable Change Scores – 1+ scorers (*n*=155)					
SIB Freq	3.92	1-16	3.363	.681	5.27
SIB Sev	3.14	1-10	2.315	.627	3.92
SIB Total	6.59	1-30	6.311	.824	7.35
ADB Freq	4.20	1-18	3.631	.792	4.59
ADB Sev	4.28	1-15	3.397	.788	4.33
ADB Total	6.71	1-36	6.909	.893	6.26
SB Freq	8.77	1-45	8.262	.867	8.35
BPI-S Total	13.04	1-84	14.537	.915	10.37

Table 6. Reliable Change scores.

To demonstrate how the data were calculated, using the Jacobson & Truax (1991) formula ($SE_{diff} = SD_1\sqrt{2\sqrt{1}} - r$) for the SIB subscale as an example (Table 6), in the total population sample, where SD_1 is the standard deviation (4.183) and r is the Cronbach's alpha internal consistency score for that subscale (.824):

$$SE_{diff} = 4.183\sqrt{2\sqrt{1}} - .824$$

$= 4.183*1.414*.420 = 2.484$

$RC = 1.96 \times 2.484 = 4.87$

Hence change that exceeds 4.87 on the SIB subscale for total population samples can be regarded as reliable. In our total population sample, change in total BPI-S score of 5.30 would indicate reliable change, as would 6.66 in SB and 4.50 in ADB.

How to use Reliable Change scores

As an example of how to use these RC scores, a housing provider monitored all challenging behaviour utilising the BPI-S on an annual basis. The majority of their population displayed no challenging behaviour so they utilised RC scores for a total population sample (Table 6). One adult was supported in single-occupancy independent living arrangement. The service provider had completed the BPI-S rating scale which gave a SIB product score of 4. Following a change in accommodation and a move into alternate congregate care provision the local authority repeated the measure twelve months later and discovered the BPI-S SIB product score was 10 – an increase of 6. The provider looked at table 6 and using the RC score for population samples, noted the SIB RC score was 4.87, indicating for this individual statistically significant deterioration in self-injurious behaviour had occurred. This alerted the housing provider to an issue following the move and an urgent case review was held.

As a second example, a PBS practitioner received a referral for an individual who engaged in high levels of stereotypy and for who a score of 21 was obtained on the BPI-S SB subscale at baseline. Following a function-based intervention, the BPI-S assessment was repeated 10 months later and the individual scored 4 at post-test. Using table 6, and scores for services focusing on people with some challenging behaviour (1+ samples), the RC score for stereotypy is 8.35. In this case a reduction of 17 is greater than the RC score of 8.35 demonstrating statistically significant improvement to behaviour. When the PBS practitioner looked at table 5 they also found that the individuals post intervention score of 4 was below the 5.66 cut off score for the stereotypy scale demonstrating clinically significant as well as reliable behaviour change.

Conclusions

The BPI-S is an informant based rating scale to assess the occurrence and severity of problem behaviour in individuals with ID. In this paper, information on the BPI-S was extended by providing population reference data, clinically significant cut-off scores, and reliable change scores. Examples provided throughout the paper show how the BPI-S can be used to facilitate clinical decisions about behaviour change. The main strength of our approach is using data from a population sample of adults with ID to derive clinically meaningful information for use in practice.

One potential limitation is that the criteria established to estimate reliable change may be particularly conservative. Reliable change scores required to establish statistically significant behaviour change are substantial (e.g. the RC score for ADB for those with problem behaviour (1+ scorers) is 6.26 compared to the mean ADB score of 6.71 in this cohort). Jacobson, Follette, and Revenstorf (1986. 350) note that the formula utilised does have the potential to make psycho-social interventions look less effective due to the conservative nature of the criteria. A further point to note when utilising the clinically significant cut-off scores is that it has been suggested that Jacobson and Truax’s (1991) “return to normal” criterion may accurately reflect the perspective of the individual who has transient situational increases in challenging behaviour, but may not be so helpful for those whose challenging behaviour is more chronic and persistent (Wise, 2004).

A more significant limitation of the data is the level of skewness (see Table 2). Positively skewed data are common in problem behaviour rating scales (Rojahn *et al*. 2012a), even in total population samples. This means that score distributions are more likely to violate assumptions of normality and potentially distort calculations of cut-off points and RC (Connell *et al*. 2007; Martinovich *et al.* 1996). The distribution is determined by the characteristic being measured, and in the case of behaviour problems or even challenging behaviour the majority of participants will present little or no challenging behaviour. It is unclear how robust the formulae’s given by Jacobson and Truax (1991) are for non-normally distributed data and how well cut-off scores and RC are estimated (Evans *et al.* 1998).

There have been efforts to improve on these formulas, by using interval data for example, but these approaches have resulted in few differences in the classification of clinical significance (Anderson *et al.* 2005; Atkins *et al*. 2005). There has been continued debate between researchers regarding an appropriate formula with some (e.g. Speer, 1992) criticised for trying to replace a simple, if potentially biased value, with one that is almost certainly still biased and not simple (Hageman & Arrindell, 1993; Evans *et al*. 1998). Hageman & Arrindell (1993) believed Speer's (1992) criticism of the original formula was erroneous and proposed a new formula entitled RC_{ID}. This new formula was itself later criticised as erroneous by Maassen (2001) in the paper 'the unreliable change of reliable change indices'. Having reviewed the literature Maassen (2000 and 2001) advocates for the continued use of the classical Jacobson and Truax (1991) approach.

This Jersey based sample is not representative of the overall UK population, therefore the findings might not generalise to the UK. One potential solution to this issue will be to pool future population data on the BPI-S. Jacobson and Truax (1991) suggest to avoid the problem of different cut-off points, scores could be standardised by aggregating samples between studies. For example, Anderson *et al*. (2005) calculated clinically significant cut-off scores and RC scores for the Revised Dyadic Adjustment Scale (RDAS) using aggregated samples. Given similar skewness in this model, the authors pooled data across studies that had used the RDAS in population samples thus reducing the potential for bias. Once further BPI-S data is collated in population samples this will be a useful exercise. Until then practitioners should express some caution against a too rigid application of the presented fixed cut-off point (Connell *et al.* 2007: 73). As well as utilising the BPI-S measure and corresponding RC scores to demonstrate behaviour change, it may also be advisable for services to capture pre and post direct and indirect behaviour data to further assist the demonstration of intervention success.

Further research is required to establish whether the BPI-S may be better suited to higher frequency of problem behaviours (Mascitell *et al.* 2015). The BPI-01 (Rojahn *et al.* 2001) may be a useful alternative in clinical settings as it contains more behavioural items and may be better suited for low prevalence items especially for self-injurious behaviour given the lower α-coefficients for the SIB subscale (Rojahn *et al*. 2012a).

Other indirect and direct data collected as part of the routine practice of function-based assessment and intervention plans should still inform decision making. Utilising the BPI-S alongside other data allows a more robust evaluation that enables clinically significant and reliable change to be determined. Practitioners should additionally consider mediator and environmental factors, risk and quality of life impacts of behaviour problems, which will inform clinical decision making within cases".

In summary, the BPI-S is a useful assessment tool for challenging behaviour in individuals with ID (Mascitelli *et al.* 2015). Population norms, clinically significant cut-offs, and reliable change scores were produced from a total administrative population sample of adults with ID within a specified geographical area. These statistics further develop the BPI-S as valuable behaviour rating tool for researchers and clinicians.

CHAPTER 5

Outcomes from a peripatetic Positive Behavioural Support service for children and adults with developmental disabilities.

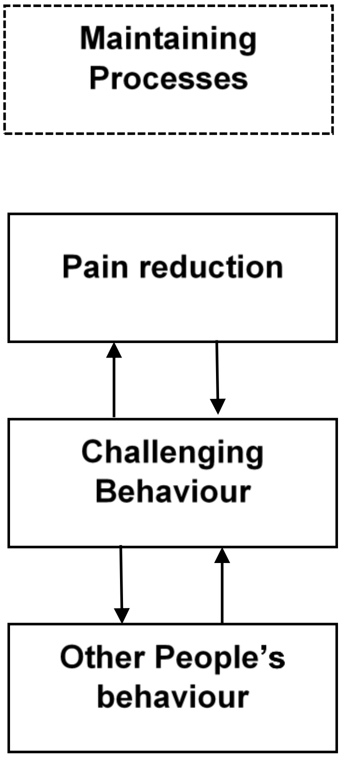

Figure 1. Maintaining Processes: Framework for understanding why challenging behaviour occurs (Hastings et al. 2013).

The focus of chapter 5 is on the evaluation of outcome data from a Positive Behaviour Support service in Jersey. Previous research studies had indicated that challenging behaviour was very common in individuals with ID (Chapter 2) and the impact can be high levels of psychotropic medication use (Chapter 3) and other aversive and restrictive practices. Positive Behaviour Support is a framework model to address vulnerabilities, whilst avoiding the aversive impact factors of other treatment approaches (Hastings *et al*. 2013). PBS also crucially focuses on the maintaining processes described in the framework (figure 1) with functional behavioural assessments a key component (Gore *et al*. 2013).

Chapter 5 addresses the lack of previous research on peripatetic PBS teams in community settings. Utilising the BPI-S reference data developed in chapter 4, behaviour change is evaluated against the clinically significant and reliable change scores provided. This chapter also provides outcome data on quality of life and social validity impacts which have been missing from previous studies.

Abstract

Background. Positive Behavioural Support (PBS) is a multi-component framework to improve quality of life (QoL) in individuals with developmental disabilities (DD) and reduce levels of challenging behaviour. Initial evidence suggests PBS may effectively impact challenging behaviour, but previous studies have not investigated whether reported behaviour change is both statistically reliable or clinically significant. Very few studies have reported QoL outcomes.

Methods. Data were collected on 85 participants referred to a peripatetic PBS service in Jersey. Functional behaviour assessments were completed and PBS intervention plans collaboratively developed with stakeholders. Challenging behaviour and QoL were measured at baseline and follow-up using the Behavior Problems Inventory – Short Form (BPI-S), adapted Kincaid (2002) QoL measure, and the EQ5D 3L / VAS health related QoL (HRQoL) measure.

Results. Statistically significant improvements in QoL and HRQoL, with medium to large effect sizes, were demonstrated following PBS input. Mean BPI-S scores reduced from 37.74 (SD=30.54) at baseline to 12.12 (SD=12.24) at follow up, with a large effect size (d=0.84). Statistically reliable behaviour change, in at least one BPI-S category, was experienced by 62 participants (72.94%) and clinically significant behaviour change by 53 participants (62.35%).

Conclusions. These data add to the evidence on the effectiveness of peripatetic PBS teams. This study included a larger sample size than previous studies, in community settings, and demonstrated the clear impact of PBS on QoL as well as clinically significant behaviour change. PBS interventions are expected to be perceived as valuable and effective by stakeholders and this study also uniquely demonstrates positive social validity outcomes. Implications for future research and policy/practice are suggested.

Keywords Positive Behavioural Support, quality of life, challenging behaviour, peripatetic, developmental disability.

Introduction

Positive Behavioural Support (PBS) is a multi-component framework to improve quality of life in individuals with developmental disabilities (DD) and reduce levels of challenging behaviour (Carr *et al*. 1999; Horner, 2000; Fox & Emerson, 2010; La Vigna & Willis, 2012; Toogood *et al*. 2015). In recent years, there has been increased alignment in the UK to the PBS model (Ball *et al*. 2004; British Psychological Society, 2004; RCP/BPS/RCSLT, 2007; Royal College Psychiatrists 2016) which has featured in government policy (Department of Health 2012a, b, 2013, 2014) and national clinical guidelines (NICE, 2015, 2017; Skills for Care, 2014). There has also been progress in terms of defining PBS and documenting the multi-elements that, featured together, make up the PBS Framework (Gore *et al*. 2013).

PBS approaches are directly underpinned by Applied Behaviour Analysis [ABA] (Ball *et al.* 2004; DHSSPS, 2002; Gore *et al*. 2013; Mansell 2007) with functional behaviour assessments a critical part of this process (Gore *et al*. 2013). A key requirement of PBS is developing an understanding of the challenging behaviour based on a prior functional assessment of the social, physical environment and context in which it occurs. This informs how the existing behaviour helps the individual manage or exert control over their environment which informs the development of a more effective, person-centred intervention plan (Iwata *et al.* 1982; Sprague & Horner, 1995; O Neil *et al*. 1997; Didden *et al.* 1997; McGill 2013; O Neil *et al*. 2015). The functional assessment process and development of intervention plans in PBS is a collaborative endeavour, with the participation and perspectives of stakeholders central to the process. The overarching goal of PBS, and the key feature of intervention plans, is to enhance quality of life for the individual and stakeholders based on system change methods (Allen *et al.* 2005; Carr, 2007; Carr *et al*. 2002; La Vigna & Willis, 2012; Gore *et al*. 2013). PBS has developed from values based movements including social role valorisation (Wolfensberger, 1983) and self-determination (Wehmeyer, 1999) which emphasises supporting individuals with DDs to be the primary causal agent in their own life (Carr *et al.* 2002). The aim of PBS is to make challenging behaviour “irrelevant, inefficient, and ineffective” (Carr *et al*. 2002. p3) by helping individuals to achieve their life goals. PBS plans thus promote lifestyle change giving individuals choice and control over their lives, include educational aspects of skill teaching that promote adaptive skills, increase engagement levels in personally stimulating activities and promote personal relationships (Gore *et al*. 2013).

Initial review evidence suggested that PBS can lead to significant reductions in challenging behaviour (Carr *et al*. 1999; Lavigna & Willis, 2012). A meta-analytic review examined 109 studies published between 1985 and 1996, including 203 participants, and concluded that PBS was effective in reducing challenging behaviour in two-thirds of cases, while success rates improved when interventions were based on prior functional assessment (Carr *et al*. 1999). LaVigna and Willis (2012) reviewed outcome data from 12 studies published between 1985-2012 that had evaluated multi-element PBS plans in 423 individuals. La Vigna and Willis (2012) concluded that PBS appeared to be effective for severe challenging behaviour, for high or low rate behaviours, and for individuals supported in institutional or community care. Further, evidence suggested PBS was cost effective and could be taught and disseminated to practitioners in the field (La Vigna & Willis, 2012). While it has also been suggested that PBS could achieve gains in adaptive skills and improve QoL (Carr *et al*. 1999), there is currently no evidence to support these suggestions as these outcomes have not been systematically included in evaluations (c.f., La Vigna & Willis, 2012).

Within the UK, support to address challenging behaviour has predominantly been provided by peripatetic community teams. It is now 30 years since the first peripatetic challenging behaviour team was launched in the UK: South East Thames Regional Health Authority's Special Development Team (Emerson *et al*. 1987). Many of these early teams published descriptions of their functions and some provided encouraging preliminary outcome data (McBrien, 1994; Allen & Lowe, 1995; Toogood *et al.* 1994ab; Lowe *et al*. 1996; Forrest *et al*. 1996; Emerson *et al.* 1996; McGill, 2000). More recently, interest in the peripatetic team model has increased (Toogood, 2016) as an alternative to much criticised current models of assessment and treatment units implicated in abuse scandals (e.g. Winterbourne View facility). Davison *et al*. 2015 indicated that 47% of the 46 peripatetic challenging behaviour services identified in the UK described themselves as being based on the principles of PBS. A further 27% described their approach as eclectic, 20% based on behavioural models and 7% on positive psychology. There have been very few evaluation studies of peripatetic team that operate using PBS in everyday community settings and the evidence base for peripatetic challenging behaviour teams utilising PBS approaches remains limited, unclear, and at a preliminary stage (Lowe *et al.* 1996; McLean, Grey & McCraken, 2007; Mckenzie, 2011).

The most robust study to date was a single blind, randomised control trial involving 63 participants (Hassiotis *et al*. 2009). Thirty one adults with challenging behaviour received standard treatment from a community based multi-disciplinary team that included a range of services including nursing, medication, and adaptive skill support. Thirty two participants received this standard service plus input from a specialist behaviour therapy team. According to researchers, staff were qualified in ABA and the team operated using principles of PBS, although a clear description of the multi-element intervention plan was not provided (Hassiotis *et al*. 2009). Researchers reported greater improvement in challenging behaviour measured at three and six months post intervention using the Aberrant Behaviour Checklist [ABC] (Aman *et al.* 1986) for the group that received additional behaviour team input. There was also improvement in mental health measured using the PAS-ADD co-morbid organic disorder subscale (Prosser *et al*.1998).

Other research evaluations have featured smaller sample sizes with less robust research designs. A study in Ireland utilised a multiple baseline design across 5 individuals in community settings (Mclean, Grey & McCracken, 2007). The frequency and duration of challenging behaviour was recorded by care staff using an agreed definition from Johnson and Pennypacker (1993) and QoL assessed using the Quality of Life Questionnaire (QoL-Q: Schalock *et al.* 1989). Behaviours were reported to fall to near zero levels for all 5 participants following PBS implementation and improvements were sustained over 24 months (McLean *et al*. 2007). The evidence for QoL improvements was less convincing with QoL-Q scores improving for only 3 of the 5 participants. The use of psychotropic medication was reduced by 66% across participants.

A further study (McKenzie & Patterson, 2010) explored a nurse led peripatetic team which offered assessment and intervention for individuals with challenging behaviour at risk of placement breakdown utilising a PBS approach. After 12 months the service had received 30 referrals and in 15 cases input had been completed and the cases closed. At this 12 month point researchers examined existing team records and used a custom-made questionnaire to gain feedback from 24 professionals: 6 staff members, 11 members of the local community team, and 7 staff from support services who had received input. Results indicated that after one year of input, 71% of service users showed a reduction in challenging behaviour. The study was limited by the small sample size and the fact the questionnaires lacked reliability and validity. There was also no examination of changes in QoL.

Allen *et al.* (2011) reported preliminary outcome data for two challenging behaviour services involving 26 participants using data tools which measured challenging behaviour and QoL at the point of referral and later at discharge. In this group, there was a significant reduction in challenging behaviour scores (measured with the ABC - Aman *et al.* 1986) from baseline to point of discharge, although actual time scales are not specified. There was a statistically significant increase in QoL measured by the Guernsey Community Participation and Leisure Assessment [GCPLA] (Baker, 2000) and in adaptive functioning measured by the Adaptive Behaviour Scale (Nihira, Leland & Lambert, 1983), plus some reductions in restrictive practices such as breakaway techniques, restraint, medication and seclusion. The authors pointed out limitations including the small sample size and the fact the reliability of the data collected was not yet established and would only be investigated in further studies.

An additional study (Inchley-Mort *et al.* 2014) compared 24 service users who had input from a complex behaviour service (CBS), based on principles of PBS, to 22 who had no input. Using the ABC (Aman *et al*. 1986) the CBS group showed significant reduction in ABC scores initially, but these did not maintain and there were only between group differences in stereotypy at 12 months and no between group differences in secondary outcomes [e.g. Mental health measured by PAS-ADD (Prosser *et al.* 1998); or Health of Nation Outcome Survey-LD (HoNOS-LD; Roy *et al.* 2002)].

There are some important limitations regarding the studies described above. Conclusions were based either on relatively small samples; research designs were not very robust (no comparison group or no baseline evaluations); outcomes measures were not always psychometrically sound; there was a lack of clarity on what interventions were received, and a main focus on problem behaviour change at the expense of QoL outcomes. Where change in behaviour problems or challenging behaviour has been documented it has largely been in terms of percentage improvements, with no focus on how meaningful that improvement has been. The failure to assess changes in QoL continues to be a key feature of studies that explore the impact of PBS delivered by peripatetic teams (McLean *et al*. 2005). Yet, even fewer studies have considered the wider social validity impact of these approaches (Kincaid *et al.* 2002; Carr *et al*. 2002). The support of peripatetic teams and the impact of their interventions need to be perceived as valuable and important by all those involved in the assessment and intervention process (Kazdin & Matson, 1981) and evaluations need to explore this dimension of PBS implementation. Whilst studies suggest encouraging initial results from the peripatetic PBS team model, particularly in reducing challenging behaviour, wider implantation of this model cannot be recommended without further exploration and research evidence into the meaningful nature of behaviour change, QoL and social validity impacts (Inchley-Mort *et al*. 2014).

The aim of the present study was to contribute further evidence on PBS effectiveness whilst also addressing a number of limitations present in previous evaluations of outcomes from specialist PBS services. We evaluated the impact of PBS as implemented by a peripatetic community team serving the entire population of Jersey, Channel Islands. Jersey is a British Crown Dependency, a small island located 22 kilometres off the coast of Normandy, France. We aimed to evaluate PBS in a larger group of participants compared to existing evaluations, and focus on effects of both QoL and challenging behaviour. We considered both statistically significant and clinically significant change as metrics for successful outcome. We also evaluated social validity to explore whether stakeholders subjectively felt that PBS input had reduced challenging behaviour to a meaningful extent and whether it had made a difference to their and the individual's QoL.

Method

Participants

The present study drew on 93 individuals who were referred to the PBS team (referral form: Appendix N) between January 2012 and December 2015 and met study inclusion criteria (see below). Of those 8 were lost to follow up (due to death, relocation or withdrawal from service), leaving 85 participants as the overall sample for this study. Participants were 39 children / young people (age up to 17 years) and 46 adults (age 18 years and older). The mean age of participants was 25.38 (SD=19.27; range 3 to 73 years). The majority of participants were female (68.2%) and 45 (52.9%) had a diagnosis of autism (13 autism and no ID; 32 autism and ID). Reasons for referral as indicated by referring agents were: aggressive or destructive behaviour (ADB: 72.9%), ADB and self-injurious behaviour (ADB & SIB: 8.2%), ADB and stereotypy (ADB & SB: 2.4%), SIB (10.6%), SB (3.5%) or other behaviour (2.4%: one was for 'deliberate incontinence' and the other 'absconding from school'). Secondary behaviours listed included incontinence (5.9%), sleep disturbance (3.5%) and dropping to ground (2.4%).

Setting

The PBS service in Jersey comprises two Behaviour Advisors and a Behaviour Advisor Assistant. All three staff are qualified to Masters level and the Behaviour Advisors have Master's degrees in ABA. The service is part of the local Health and Social Services (H&SS) and is fully integrated within the Community and Social Services multi-disciplinary service alongside social workers, nurses, occupational therapists, physiotherapists, speech and language therapists, psychologists and psychiatrists. The service works with individuals of all ages with a diagnosis of intellectual disability (IQ<70) and / or autism. The service was established in 1999 with the aim of promoting community integration for adults with ID whose behaviour challenges, many of which at that time were placed in a residential hospital which was closed in 2004. Jersey has no large residential facility and at the time of writing had no individuals placed off-island for challenging behaviour treatment. The population of Jersey during the data collection process was 102,700 (States of Jersey, 2015). Given suggested prevalence rates of ID and Autism (ID 2%, BPS 2011; Autism 1% Baird *et al.* 2006), this would suggest a potential population of 2054 individuals with ID and 1027 with Autism (some of these will also have an ID).

There are three key tasks performed by the service. The first is case work. Referrals are received from many sources including parents / carers, service users, and professionals including paediatricians, Child and Adolescent Mental Health Service, social workers, GPs and staff in education. Where specific advice regarding challenging behaviour is required functional behaviour assessments are completed which inform the development of Positive Behaviour Support Plans. The service also receives referrals for one-off or intermittent case advice which may not meet the above criteria. The team operate a monthly 'drop-in clinic' where advice can be sought by professionals and carers on a range of behavioural issues. Sometimes, advice is sought on issues that are not strictly challenging behaviour related, such as sleep issues, intolerance to personal care tasks and food refusal. Sometimes advice is sought for individuals without a clear diagnosis of a DD, but given the small island community the team is often deemed in the best position to provide advice or sign post to other professionals following input. Additionally, requests may be received to attend intermittent professionals meetings, such as safeguarding meetings, risk reviews, or to review historical behaviour support plans. The team can also be asked to be involved in the management of transitions, service / housing design or Active Support initiatives (Totsika *et al.* 2008).

During the period of data collection there were total case referrals of 76 referrals in 2013 (33 aged $\leq$17 years; 43 aged $\geq$18 years), 88 in 2014 (28 aged $\leq$17 years; 50 aged $\geq$18 years), and 75 in 2015 (34 aged $\leq$17 years; 41 aged $\geq$18 years). For the purposes of this study, data were collected on the 85 individuals, who had DDs with challenging behaviour, who required a functional assessment and PBS intervention plan. Drop-in clinic cases, or one-off meeting requests, were not considered appropriate for inclusion in this study due to the brief nature of input, difficulties gathering baseline and follow-up measures, along with the potential lack of defined challenging behaviour and DD diagnosis.

The PBS team also provides PBS training courses, writes and reviews the local Health and Social Services Positive Behaviour Support Policy, and contribute to wider service planning and design, within the States of Jersey, to influence the wider implementation of PBS approaches.

Measures

Quality of Life Tool (Kincaid et al. 2002)

In a systematic review Townsend-White *et al*. (2009) found no specific instrument to measure QoL in people with DDs and challenging behaviour. Appendix S details the tools considered for use in this study which were evaluated against a number of factors including cost, length and face validity. As no existing tools were ideal, QoL outcomes were assessed using an adapted version of Kincaid *et al's.* (2002) scale. The original 22 question measure has good interitem reliability (.95 for overall quality of life and .73-.90 for each scale). It assesses 5 domains: interpersonal relationships, self-determination, social inclusion, personal development and emotional wellbeing. These align well with the goals of a PBS service. However, the original measure was child-focused, used American language and was not formatted for repeated assessments. A shorter eight question version covering the five QoL domains was developed with permission from the authors. This was primarily for ease of research given time demands on participants in completing all measures. We reduced the number of items by deleting similar ones in each domain and removing analogous ones, whilst maintaining all dimensions. For the child version we completed readability analysis and amended item statements to ensure scores of above 60 on the Flesch reading scale and below 8 on the Flesch-Kincaid Grade Level (Kincaid *et al.* 1975). A parallel eight question version for adults was developed which included the same questions / domains but worded items slightly differently (e.g. Question 2: Child measure: The child / young person gets on well with family members; Adult measure: The person gets on well with people they live with). Each item statement was measured with a five point Likert-type scale ranging from 1 to 5, with a score of 1 indicating *strongly disagree* and a score of 5 indicating *strongly agree* (See tables 1 and 2). Proxy informants were asked to rate each statement based on the individual's life over the previous two months. The adult scale was used for individuals aged 18 and over. The child scale was used for individuals aged 17 and under. Children who were 16 or 17 and not living at home or accessing education were administered the adult scale. Participants could score a maximum of 40 on this scale with a larger score indicating higher levels of QoL. Cronbach's alpha for the eight question QoL child measure at baseline was .698 and for the adult scale .842 (Child/young person QoL Scale: Appendix Q; Adult QoL Scale: Appendix P).

Health Related Quality of Life: EQ-5D (https://euroqol.org/)

To measure HRQoL the EQ-5D 3L (version 1) proxy measure was utilised (Appendix R). The EQ-5D is a standardised measure of HRQoL developed by Euroqol to provide a simple, generic measure of health for clinical studies (Euroqol, 1990). The EQ-5D has been used successfully in previous studies involving individuals with DDs (Boland *et al*. 2009). The EQ-5D 3L describes function and QoL across five dimensions – mobility, self-care, usual activities, pain or discomfort, and anxiety or depression. Each dimension has three levels – no problems, some problems, and extreme problems - which generates a potential 243 health states. The proxy informant rates the most appropriate statement in each dimension for that individual at that moment in time. Health states can also be converted into a summary statistic by applying a formula that attaches values or weights to each level. The present study used the corresponding UK Time Trade Off (TTO) value set as advised by Euroqol (MVH group, 1995; Dolan, 1997). This converts one of the 243 potential health states into an index value ranging from 0 to 1 where 1 represents full health. Proxy informants also rated the EQ-5D Visual Analogue Scale (VAS) – a quantitive index of self-perceived health status

(Appendix R). This records the proxy's subjective view of the individual's health status in that moment in time where 100 represents *best imaginable health* and 0 *worst imaginable health*.

Behaviour Problems Inventory – Short Form (Rojahn et al. 2012a).

The Behaviour Problems Inventory – short form (BPI-S) measures three of the most common challenging behaviour topographies shown by individuals with ID (Rojahn *et al.* 2012a). The BPI-S (Appendix I) is a standardised rating scale, with good reliability and validity to assess challenging behaviour in individuals with ID (Mascitelli *et al.* 2015; Rojahn *et al.* 2012a, b). It has been demonstrated to have adequate to good internal consistency (Bowring *et al*. 2017a / Chapter 2; Mascitelli *et al.* 2015; Rojahn *et al.* 2012a, b), inter-rater agreement and test-retest reliability (Mascitelli *et al*. 2015), strong evidence for confirmatory and discriminant validity (Rojahn *et al*. 2012a, b); and confirmatory factor analysis has validated the three BPI-S subscales (Mascitelli *et al*. 2015).

The BPI-S comprises thirty items arranged in three subscales: the Self Injurious Behaviour (SIB) subscale (eight items), the Aggressive Destructive Behaviour (ADB) subscale (ten items), and the Stereotyped Behaviour (SB) subscale (twelve items). Each item is rated on a five-point frequency scale (never = 0; monthly = 1; weekly = 2; daily = 3; hourly = 4) and a three-point severity scale (mild = 1; moderate = 2; severe = 3). Frequency and severity of behaviour are measured for the SIB and ADB subscales, and frequency alone for the SB subscale. For each item, a score is generated by multiplying the frequency and severity scores and the sum of these product scores generates a subscale score. The sum of the three subscales gives a BPI-S total score. We asked raters to consider behaviour present in the past two months for this current study.

Social Validity Survey

Social validity was measured using six statements about the impact on carers/keyworkers (e.g. *I am more effective in preventing challenging behaviour occurring* and *there are fewer injuries / the environment is damaged less than before*), and seven statements about the impact on the target individual (e.g. *People view X more positively than before* and *X is able to communicate his / her needs more effectively*) [measure sourced from Behaviour Support

Team, North Wales, NHS Trust: Appendix O]. Informants rated statements on a 5 point Likert scale from 1 (*strongly agree)* to 5 (*strongly disagree).* Social validity was measured only at follow up. Cronbach's alpha for the 13 question measure was excellent at .847.

PBS Intervention

PBS allows flexibility in the assessment process in natural community settings (Carr *et al.* 2002). Types of data may vary, but data are always collected to guide and evaluate intervention decision making. Functional assessments may include the following:

- Functional assessment interviews (e.g. O Neill *et al.* 1997).
- Rating scales (e.g. Motivational Assessment Scale: Durand & Crimmins, 1992; Questions About Behavioural Function: Matson & Vollmer, 1995).
- Indirect data collation (e.g. episodic severity records, frequency records, Antecedent-Behaviour-Consequence records).
- Observational direct data (e.g. time sampling).
- A review of previous assessments reports (e.g. Educational Psychology reports, sensory profile assessments) and other data logs (e.g. service incident records, or daily logs).
- Functional Analysis.

Some challenging behaviour is complex and requires more detailed assessment to establish function. Decisions about the extent of functional assessments were taken by the service's Behavioural Advisors. They considered the function of challenging behaviour, and potential interventions required. Functional analysis, where antecedents and consequences are manipulated "experimentally" to understand their effects, may be employed, but very rarely in these community settings given the risks and ethical implications of deliberate manipulations that invoke target behaviour. More information on service working practices can be obtained from the author.

Once the functional assessment was completed, PBS Team staff presented results to stakeholders and used results to develop the multi-element PBS intervention plan. This process is a collaborative endeavour to ensure good contextual fit (Albin *et al.* 1999). PBS plans focused on person-centred approaches that promoted QoL. PBS plans included:

- A definition of the challenging behaviour.

- A shared understanding of the function of the challenging behaviour.
- Key indicators of behavioural agitation.
- Proactive strategies that are preventative: e.g. proactive management of physical and mental health; communication approaches; strategies that modify the antecedents that evoke challenging behaviour; ABA evidenced behavioural technology such as differential reinforcement of other behaviours; strategies that promote person centred QoL and give the individual choice, control, engagement; strategies that promote relationships and community participation.
- Proactive strategies that are developmental: e.g. teaching new behaviours; promoting skills; teaching functionally equivalent behaviours; teaching coping and tolerance skills.
- Secondary strategies: e.g. approaches to support the individual at early signs of distress: stimulus change; diversion to preferred activities; active listening; change interactor or interactional style.
- Reactive strategies to reduce immediate risks and promote safety: e.g. first resort strategies (La Vigna & Willis, 2012) such as strategic capitulation and last resort strategies based on least restrictive approaches.
- Wider system approaches: e.g. staff / carer training; support for carers.
- Details of the review process: e.g. type of data tool to evaluate progress; name of person responsible for review; scheduled date of review.

Procedure

Measures were completed at baseline and follow-up by a proxy informant. A decision was made to draw data from proxy informants so as to ensure consistency in reporting for individuals at all levels of communication abilities (Chowdhury & Benson, 2011). To identify the most appropriate proxy informant, researchers initially discussed with the referrer the key people who knew the individual best. It was agreed that for children (aged 17 years and under) a parent / main carer should be proxy if the challenging behaviour was present in the home environment; a teacher / tutor should be proxy if the challenging behaviour was specific to an education environment; and a key-worker / carer should be proxy if the challenging behaviour was specific to a care / respite environment. If the referral was for an adult (18+ years) a parent / main carer should be proxy if the individual lived at home and the challenging behaviour was present in the home environment; a keyworker / main carer should be proxy if the individual lived in a staffed residential or accessed a day service setting and the challenging behaviour was present in this setting; and a lead professional (e.g. community nurse), support worker or parents could be proxy if the individual lived independently, by evaluating who had the most contact and knowledge regarding the individual. In all cases, the proxy identified was expected to have continued contact with the individual during PBS service input period and be available to complete the follow-up measures.

Data were collected by PBS team practitioners directing the interventions, as a routine part of clinical practice. All data were collected in face-to-face interviews with the proxy informants. Baseline measures were completed by the Mother (n=31), Father (n=2); both parents (n=7); Grandmother (n=1), keyworker/health care assistant/support worker (n=32), nurse (n=5), social worker (n=4); teacher (n=2), or respite co-ordinator (n=1). There were the same respondents at follow-up as baseline in 83 cases, with two community nurses completing follow-up measures instead of one mother and one health care assistant. The mean time between baseline and follow-up was 45 weeks (SD=29.19), median=37 weeks; range 15-160 weeks.

Measures were all completed with the proxy informant at baseline prior to any input from the PBS service. Once the case was opened a functional assessment was completed, a PBS intervention plan put in place with stakeholder input, and time and support was given for individual advice to be implemented. Follow-up measures were completed after a suitable time period was allowed for implementation of PBS plans and consideration of the two month assessment review period of the measures. The timing of the follow-up evaluation was tied to service processes and discussed between Behaviour Advisors and stakeholders during regular review meetings. If stakeholders felt progress was positive in reducing challenging behaviour and improving QoL, follow up assessments were completed. If follow-up results confirmed progress then discharge was agreed and social validity surveys were completed. Arrangement for the withdrawal of team support and case closure was made on an individual basis in agreement with the referring agents and stakeholders. This was usually at the point of acceptable improvement in referral problems. Occasionally stakeholders / referral agents continued to oversee implementation of key interventions that had still not been finalised (e.g. environmental adaptions / staffing changes) or alternative professionals reviewed case progress (e.g. social workers / nurses) following requests from the PBS team.

Ethics

Ethical approval for the study was given by the University, School of Psychology Ethics and Governance Committee (Appendix L) and the States of Jersey Health and Social Services Ethics Committee approved the study as a service audit (Appendix M). Approval to use anonymously collected service data was given by the Director of Community Services, H&SS, Jersey. Participants, or their consultee under Jersey law, gave consent for their outcome data to be used for research/evaluation purposes documented at the point of referral (Appendix N).

Approach to Analysis

Changes in mean QoL, EQ5D 3L index scores, EQ5D VAS, and BPI-S scores were calculated between baseline and follow-up. As a separate children and adults tool was used for QoL, results were calculated for both groups using this measure. Paired sample t-tests were used to explore change from baseline to follow-up along with d-based effect sizes that adjusted for repeat data collection (Dunlap *et al*. 1996); magnitude of effect size could then be established (Cohen, 1988: 0.50 medium, 0.80 large, etc).

We supplemented the analysis by considering whether change at an individual level was meaningful and significant. A previous study (Chapter 4) had identified BPI-S clinically significant cut-off values and reliable change scores. The number of cases where clinically significant and statistically reliable change in challenging behaviour was achieved was explored. Using baseline data from the present study, and applying Jacobson and Truax's formula (1991) we calculated that the total score on the QoL measure would need to improve by a score of 7.18 to represent reliable change in QoL. Therefore, we also calculated the number of participants that achieved reliable change in QoL.

Results

Quality of Life Results. On average, participants reported higher levels of QoL at follow-up (M=33.44, SE=.36) than at baseline (M=28.59, SE=.61), t(84)=-8.60. p<.001, d=1.0. This indicates significant improvement in QoL across the five domains measured following intervention with a large effect size.

Table 1 presents QoL results for the children’s / young people’s version. There were higher levels of quality of life reported at follow-up (M=33.13, SE=.53) than at baseline (M=28.67, SE=.75), t(38)=-7.10, p<0.001, d=1.07. Table 2 presents QoL results for the adult version. There were similarly higher levels of quality of life reported at follow-up (M=33.70, SE=.50) than at baseline (M=28.52, SE=.94), t(45)=-5.76, p=<0.001, d=0.98.

Twenty one participants (24.71%) demonstrated reliable change in QoL.

			Strongly disagree % 1	Disagree % 2	Neither agree or disagree % 3	Agree % 4	Strongly agree % 5	MEAN
1.	The child / young person has lots of chances to express personal choices on a daily basis.	Pre:	2.6	5.1	20.5	33.3	38.5	4.00
		Post:	0	0	5.1	51.3	43.6	4.38
2.	The child / young person gets on well with family members.	Pre:	2.6	25.6	20.5	38.5	12.8	3.33
		Post:	0	2.6	7.7	59.0	30.8	4.18
3.	The child / young person is willing to try new tasks or activities.	Pre:	12.8	17.9	25.6	30.8	12.8	3.13
		Post:	5.1	5.1	20.5	51.3	17.9	3.72
4	The child / young person has chances to interact with other children / young people at least weekly.	Pre:	0	2.6	10.3	48.7	38.5	4.23
		Post:	0	0	5.1	53.8	41.00	4.36
5.	The child / young person gets on well with adults in education or care settings.	Pre:	2.6	12.8	25.6	35.9	23.1	3.64
		Post:	0	0	10.3	53.8	35.9	4.26
6.	The child / young person has good access to local places they enjoy visiting at least weekly.	Pre:	5.1	5.1	30.8	33.3	25.6	3.69
		Post:	0	0	7.7	53.8	38.5	4.31
7.	The child / young person gets on well with other children / young people.	Pre:	2.6	30.8	30.8	28.2	7.7	3.08
		Post:	0	5.1	28.2	59.0	7.7	3.69

8.	The child / young person has chances to participate in leisure pursuits of their own choice at least weekly.	Pre: Post:	0 0	17.9 2.6	25.6 5.1	38.5 59.0	17.9 33.3	3.56 4.23

Table 1. Children / young people's QoL changes over time (n=39).

			Strongly disagree % 1	Disagree % 2	Neither agree or disagree % 3	Agree % 4	Strongly agree % 5	MEAN
1.	The person has lots of chances to express personal choices on a daily basis.	Pre: Post:	6.5 0	10.9 0	10.9 4.3	37.0 43.5	34.8 52.2	3.83 4.48
2.	The person gets on well with people they live with.	Pre: Post:	8.7 4.3	17.4 4.3	32.6 23.9	28.3 43.5	13.0 23.9	3.20 3.78
3.	The person is willing to try new tasks or activities.	Pre: Post:	4.3 4.3	37.0 2.2	23.9 21.7	19.6 45.7	15.2 26.1	3.04 3.87
4	The person has the chance to interact with people they do not live with at least weekly.	Pre: Post:	4.3 4.3	26.1 2.2	4.3 10.9	34.8 37.0	30.4 45.7	3.61 4.17
5.	The person gets on well with other adults such as friends and co-workers.	Pre: Post:	4.3 0	17.4 4.3	19.6 2.2	41.3 56.5	17.4 37.0	3.50 4.26
6.	The person has good access to local places they enjoy visiting at least weekly.	Pre: Post:	0 0	10.9 0	15.2 4.3	37.0 30.4	37.0 65.2	4.00 4.61
7.	The person gets on well with family members.	Pre: Post:	4.3 0	19.6 6.5	23.9 19.6	26.1 43.5	26.1 30.4	3.50 3.98
8.	The person has good chances to participate in leisure pursuits of their own choice at least weekly.	Pre: Post:	2.2 0	13.0 0	15.2 8.7	37.0 28.3	32.6 63.0	3.85 4.54

Table 2. Adults QoL changes over time (n=46).

EQ-5D 3L / VAS Results. There were reductions in the numbers of individuals reported to have problems in self-care, usual activities, pain / discomfort and anxiety / depression post intervention. Only one person was reported to have any improved mobility post intervention. The mean EQ5D 3L index value increased from .52 (SD=.30; 95% CI=.45 to .58) at baseline to .71 (SD=.23; 95% CI=.66 to .76), at follow up: t(84)=-6.15, p<0.001, d=0.72.

For the EQ5D VAS the mean score on the analogue scale at baseline was 74.99 (SD: 17.62) and at follow-up 83.15 (SD: 10.84): t(84)=-4.69, p<0.001, d=0.54. These results indicate significant positive change in HRQoL following intervention with medium to large effect sizes.

BPI-S Results. Table 3 presents mean BPI-S scores at baseline and follow-up. The mean BPI-S score at baseline was 37.74 (SD=30.54), compared to 12.12 (SD=12.24) at follow-up, representing a statistically significant reduction in challenging behaviour (t(84)=9.99, p<0.001) with a large effect size (d=0.84). There were statistically significant reductions in BPI-S scores in all frequency, severity and subscale categories with medium to large effect sizes. In terms of overall BPI-S score, one person scored higher at T2, but 84 people (98.82%) saw reductions in total BPI-S scores representing reduced levels of challenging behaviour.

BPI-S Mean Scores at baseline and follow-up (N=85)

	Pre Scales		**Post Scales**		**Paired t Test**			**Pearson's r**	**Effect Size**
	Mean (SD)	***Range (min-max)***	***Mean (SD)***	***Range (min-max)***	***t***	***d.f.***	*p*	***r***	***d***
SIB Freq	*3.82 (4.19)*	*15 (0-15)*	*1.49 (2.17)*	*10 (0-10)*	*6.73*	*84*	*<0.001*	*.66*	*0.60*
SIB Sev	*2.56 (3.08)*	*15 (0-15)*	*1.02 (1.52)*	*7 (0-7)*	*5.96*	*84*	*<0.001*	*.66*	*0.54*
SIB Total	*6.34 (7.98)*	*39 (0-39)*	*1.79 (2.92)*	*16 (0-16)*	*6.17*	*84*	*<0.001*	*.55*	*0.63*
ADB Freq	*10.48 (7.91)*	*40 (0-40)*	*3.54 (3.84)*	*13 (0-13)*	*11.00*	*84*	*<0.001*	*.72*	*0.90*
ADB Sev	*8.38 (6.01)*	*25 (0-25)*	*2.73 (2.86)*	*12 (0-12)*	*11.18*	*84*	*<0.001*	*.66*	*1.00*
ADB Total	*19.28 (18.01)*	*80 (0-80)*	*4.13 (4.94)*	*20 (0-20)*	*9.35*	*84*	*<0.001*	*.70*	*0.78*
SB Total	*12.12 (11.27)*	*41 (0-41)*	*6.20 (7.84)*	*30 (0-30)*	*7.42*	*84*	*<0.001*	*.76*	*0.56*
BPI-S Total	*37.74 (30.54)*	*129 (2-131)*	*12.12 (12.24)*	*59 (0-59)*	*9.99*	*84*	*<0.001*	*.70*	*0.84*

Table 3. BPI-S Mean scores at baseline and follow-up

Table 4 presents the number of participants achieving reliable change in BPI-S categories using previously identified Reliable Change (RC) statistics for individuals scoring 1+ on the BPI-S (chapter 4). There were 51 people scoring 1+ on the SIB scale at baseline, 83 on the ADB scale, 63 on the SB scale and 85 overall. In this study 55 people (64.71%) saw BPI-S total score reductions greater than the 10.37 RC statistic (range 11-106) representing nearly two-thirds of people referred to the PBS service experiencing statistically reliable reductions in overall challenging behaviour. In terms of subscales greatest improvement was seen in the ADB category with 54 people (65.06%) experiencing statistically reliable decreases in BPI-S (scores > 6.26). For the SIB subscale, 21 people (41.18%) saw statistically reliable improvements in behaviour and for the SB subscale 26 people (41.27%).

BPI-S category	**RC Statistic (Bowring et al. 2017b)**	**Decrease in BPI-S > than RC statistic (N / %)**
SIB Freq	*5.27*	*15 (29.41%)*
SIB Sev	*3.92*	*14 (27.45%)*
SIB Total	*7.35*	*21 (41.18%)*
ADB Freq	*4.56*	*48 (57.83%)*
ADB Sev	*4.33*	*44 (53.01%)*
ADB Total	*6.26*	*54 (65.06%)*
SB Total	*8.35*	*26 (41.27%)*
BPI-S Total	*10.37*	*55 (64.71%)*

Table 4. Analysis of BPI-S score changes including reliable and clinically significant change.

Previous studies defined challenging behaviour using the BPI-S (Bowring *et al*. 2017a / Chapter 2) and produced clinically significant cut-off values (Chapter 4). A clinically significant cut-off score is a score participants must cross to move from the dysfunctional (challenging behaviour) population to the functional (scores within range of the typical DD) population. In this present study, at baseline, 50 out of 51 participants presenting SIB scored above the 1.88 cut-off score; 66 of the 83 presenting ADB scored above the cut-off score of 5.69; 52 of 63 people presenting SB scored above the 5.66 cut-off score; and of the 85 participants referred, 69 scored above the overall BPI-S cut-off score of 9.35. Using the clinically significant cut-off scores estimated in the total population study (Chapter 4), data in the present study indicated that 27 people (39.13%) presented with clinically significant reductions in overall challenging behaviour (total BPI-S scores). More specifically, of the people scoring above identified cut-off scores, 41 people (62.12%) experienced clinically significant reductions in ADB scores, 19 (38%) reduction in SIB scores and 19 (36.54%) reduction in SB scores.

Social Validity Survey Results Table 5 presents the results of the social validity survey. There were six questions on the impact of interventions for the informant and seven questions regarding the perceived impact on the participants. Results indicated a very positive view of the impact of the PBS intervention, such as 93% either agreed, or strongly agreed, that they were more effective at preventing challenging behavior occurring. Further 74% either agreed, or strongly agreed, that the participant was able to communicate needs more effectively following PBS Service input.

Social Validity Survey Results

	Strongly agree % (N=)	**Agree % (N=)**	**Neither agree nor disagree % (N=)**	**Disagree % (N=)**	**Strongly disagree % (N=)**
About you					
I know more about challenging behaviour than I previously did	*35.29 (30)*	*57.65 (49)*	*7.06 (6)*	*0*	*0*
I am more effective in preventing challenging behaviour occurring	*31.76 (27)*	*61.18 (52)*	*7.06 (6)*	*0*	*0*
When challenging behaviour occurs I can manage it more effectively	*30.59 (26)*	*62.35 (53)*	*7.07 (6)*	*0*	*0*
Challenging behaviour now stresses me less than it previously did	*12.94 (11)*	*55.29 (47)*	*30.59 (26)*	*1.18 (1)*	*0*
I am able to cope better with challenging behaviour than before	*24.71 (21)*	*57.65 (49)*	*17.65 (15)*	*0*	*0*
There are fewer injuries/ the environment is damaged less than before	*36.47 (31)*	*43.53 (37)*	*18.82 (16)*	*1.18 (1)*	*0*
About X					
There is less risk of X being excluded from home/community/school/etc.	*40.00 (34)*	*45.88 (39)*	*12.94 (11)*	*1.18 (1)*	*0*
X does more activities than s/he used to	*20.00 (17)*	*44.71 (38)*	*31.76 (27)*	*3.53 (3)*	*0*
X makes more use of the community than before	*15.29 (13)*	*45.88 (39)*	*35.29 (30)*	*3.53 (3)*	*0*
X has more (or improved) relationships with others	*11.76 (10)*	*65.88 (56)*	*17.65 (15)*	*4.71 (4)*	*0*
People view X more positively than they did previously	*16.47 (14)*	*57.65 (49)*	*22.35 (19)*	*3.53 (3)*	*0*
X is now able to communicate his/her needs more effectively	*15.29 (13)*	*58.82 (50)*	*22.35 (19)*	*3.53 (3)*	*0*
X is more independent than s/he was previously	*14.12 (12)*	*44.71 (38)*	*36.47 (31)*	*4.71 (4)*	*0*

Table 5. Social Validity Survey results (n=85).

Discussion

This paper presents an evaluation of outcome data from a peripatetic PBS service and the data add to the existing preliminary evidence of the effectiveness of such teams. This study demonstrated statistically significant improvements in QoL across all 85 study participants as measured by the adapted Kincaid *et al.* (2002) QoL scale. In addition, the change was large enough so as to be considered statistically reliable for one-quarter of participants. Similar findings were present when we considered HRQoL using the EQ5D 3L and EQ5D VAS, demonstrating statistically significant improvements across all participants accompanied by medium to large effect sizes. Further exploration of the psychometric properties of the QoL measure that was developed for this study are required as it showed promise as a responsive, simple, pre and post intervention measure. The child rating should be reviewed given the lower alpha score (.698 for child measure; .842 adult measure), but the PBS field would certainly benefit from a user friendly, pre-post tool, sensitive to measure QoL outcomes (Kincaid et al. 2002; Townsend White et al. 2011). It should be noted that whilst this included domains of QoL relevant to PBS outcomes, it does not consider wider QoL domains such as material wellbeing and rights (Schalock *et al*. 2002). The results of the social validity survey add to the evidence on positive lifestyle outcomes based on subjective experiences of stakeholders. There may be additional aspects of what stakeholders were hoping to gain from PBS input not included in the measure. This study is unique in demonstrating progress in QoL, HRQoL and social validity outcomes using the PBS model in a natural community environment.

Findings also indicated that 62 people (72.94%) experienced RC in at least one BPI-S category. The greatest changes were experienced by those with aggressive destructive behaviour (65.06% saw RC in behaviour), followed by those presenting stereotypy (41.27% >RC) and self-injurious behaviour (41.18% >RC). Findings show that 53 people (62.35%) experienced clinically significant behaviour change in at least one BPI-S category. This is the first study into the effectiveness of peripatetic PBS services that has demonstrated clinically significant behaviour change using a clearly defined standard for improvement.

Results support other data that have demonstrated behaviour and QoL improvement by peripatetic PBS teams (McLean *et al.* 2007; Allen *et al.* 2011). Davison *et al*. (2015) recently surveyed 20 such UK services and examined the last three cases discharged. Using structured questionnaires designed with input from academics, practitioners and the Challenging Behaviour Foundation National Strategy Group, these teams reported reductions in challenging behaviour in 81% cases and improvement in QoL in 87%; but as in other studies the authors do not stipulate whether this change is reliable or clinically significant which is a strength of the current study. Results contribute to a growing evidence base in support of the PBS process in community settings that involve functional assessment of challenging behaviour and a stakeholder informed, PBS intervention plan that focuses on lifestyle and environmental change, with QoL changes utilised as both an intervention and outcome goal (Gore *et al.* 2013).

Despite the positive reductions in challenging behaviour, the BPI-S results in this study indicated that 32 participants (37.65%) did not experience clinically significant change, highlighting the challenge in affecting behaviour change in community settings. The primary reason for referral was aggression reported in 72.9% of participants. This is similar to referral rates for aggression seen in other PBS studies (67%: Allen *et al*. 2011; 69.5%: Toogood *et al*. 2015) indicating aggression as a prominent topography in referrals to such services. However, of those referred, 16 (18.8%) presented behaviours which challenge in just one BPI-S subscale (e.g. ADB, SIB or SB), 26 (30.6%) presented behaviours in two subscales and 43 (50.6%) presented in all three subscales. Thus, half of individuals referred to the PBS service were presenting with SIB, ADB and SB indicating a range of behaviours requiring functional assessment. Reliable change was not as apparent in data describing SB (41.27%) compared to ADB (65.06%), but this may be related to the fact only 3.5% of referrals to the PBS service mentioned SB and it may not have been assessed as a target behaviour. Additionally, only 9 (10.6%) of the 85 participants scored zero on the BPI-S follow-up measure demonstrating total extinction of challenging behaviour. Previous studies (Chapter 4) have demonstrated a level of problem behaviour within the functional ID population. PBS services should therefore have the realistic aim of clinically significant reduction in challenging behaviour using BPI-S scores as a guide (Chapter 4), with total extinction of any issues possibly rare and potentially over ambitious as a service aim.

Limitations

One of the main limitations of the existing evaluation is the lack of a comparison group. As interventions were provided as part of the routine clinical package provided by H&SS in

Jersey, there were no control groups or randomised allocation of treatment. However, given the community setting where the PBS service was operating and the ongoing responsibilities of the service model it would have been difficult to achieve a control element in this study. Reversal designs would also be impossible given the nature of PBS interventions.

Given the single group pre-post design, it is important to acknowledge that PBS team input is only one of many variables which may determine individual case success (Davison *et al*. 2015). Hence, there may be additional factors that contributed to the positive results in this study. Other factors have been suggested which may impact on PBS team success, including the quality and competence of referring environments (Lowe *et al.* 1996), levels of available support and the motivation of mediators to implement recommended interventions (Davison *et al.* 2015). Specialist PBS services may only be as good as the mainstream services they support (Toogood, 2016). In Jersey, to address this, the PBS team have a Behaviour Advisor Assistant whose role it is to support organisations and carers implement advice. This may involve direct modelling, training, coaching and advice, as well as practical support (e.g.to create visual tools or social stories). Functional assessment reports and PBS plans developed by the team were reviewed and discussed during team meetings and individual supervisions. Future research could consider the evaluation of PBS plans using quality evaluation tools (e.g Behaviour Support Plan Quality Evaluation tool (BSP-QEII), McVilly et al. 2013) and consider the fidelity of implementation using Periodic Service Reviews (La Vigna, 1994).

This study has also not demonstrated the maintenance of improvements in QoL, HRQoL and challenging behaviour. The lack of a longer term follow-up is a limitation of this study and caution should also be taken where services evaluate their own interventions such as in this study.

Directions for future research

Further consideration should thus be given to increasing the robustness of research designs in community settings where PBS services operate. One suggestion would be to consider further randomised control groups as in the Hassiotis *et al.* (2009) study. This could include support from MDT practitioners vs. MDT and PBS services, waiting list control groups, multiple baseline designs or some aspect of part PBS vs. full PBS interventions. Yet, there are clear ethical considerations given the risks and impacts of the behaviours referred, which services are tasked with addressing in community settings. If there are practitioners and services that have expertise, assessment skill and interventions to respond to situations where challenging behaviour is posing clear risks and impacting on an individual's QoL, then it will be difficult for a H&SS (in this case) to withhold input to PBS services for the benefit of an experimental research design. A recent RCT on brief staff training in PBS (Hassiotis et al. 2018) failed to conclude any impact on service user behaviour or secondary factors such as mental health and community participation. The administration of the training intervention had a number of difficulties including the fact of less than optimal delivery of the intervention with just 30% of participants receiving all elements of the PBS approach in training, and 8 of 26 staff trained leaving during the study. Resulting fidelity of PBS plans was poor and a large percentage of paperwork was not submitted. This suggests that any future RCTs of PBS should pay close attention to intervention delivery issues.

Research should also explore how changes in QoL and challenging behaviour are maintained. The measures used in this study would be appropriate and user-friendly as probes, at fixed time periods, to investigate the longer term impact of PBS. Researchers also need to explore who might benefit from PBS and who might not, and why? In addition, research is needed to ask the question of why some environments may be more responsive to PBS interventions and what are the barriers to implementation for others? This will be crucial to how PBS teams develop and adapt the future delivery of their services. Finally, the QoL measure could be a service friendly measure to be incorporated in clinical practice. Further research is required to establish the psychometric characteristics of this measure.

Implications for Practice and Policy

One aspect the BPI-S data has highlighted in this study is the complexity of presenting behaviour at pre-intervention sometimes not captured in referral documentation. A referral may be received for 'hitting others', but there were occasions where the BPI-S indicated additional behaviours that challenge including SIB and SB. This suggests peripatetic teams should consider including measures, such as the BPI-S, not just to provide a baseline measure on behaviour, but also to understand presenting behavioural issues in more detail. A key part of PBS service input is, in agreement with stakeholders, identifying the behaviours that are impacting on QoL and for purposes of functional assessment, operationally defining the behaviour to be assessed. The BPI-S, completed at point of referral, could assist these decisions and avoid reporting biases of those experiencing the behaviours. Similarly, Qol and HRQoL tools used at baseline can assist identification of areas to target and shape service goals.

The BPI-S baseline score can also be used to establish case priority or places on waiting lists for service input. The BPI-S as a follow-up measure clarifies case progress and can help decisions around case closure or the need for additional assessment work. Teams could also complete the BPI-S at future reviews or intermittent time points, following closure, to monitor maintenance.

Having capacity to provide intensive support, which includes hands-on behavioural modelling, may contribute to successful change (McLean *et al*. 2005; Toogood, 2016) and it is important services receive adequate funding to work intensively in case work. Many services, however, struggle to provide intensive support with average team caseloads of 47, individual caseloads of 8 and average length of open cases 47 weeks (Davison *et al*. 2015). The average case length was 45 weeks in this study indicating the considerable input and commitment to each case. It is positive that results indicate that significant change can occur within this time period, following intensive input, despite suggestions that efforts to achieve meaningful change through lifestyle approaches can take years (Turnbull & Turnbull, 1999). Further, given the importance within the PBS model of stakeholders perceiving interventions to be meaningful the use of social validity follow-up tools are important for services to gain feedback from stakeholders. The measure used in this study had an excellent reliability alpha (.847) and can be utilised by other services.

Policy makers should expect services tasked with responding to challenging behaviour in individuals with DD (including psychiatric services that utilise pharmacological interventions) to demonstrate clear outcome data on the effectiveness of their interventions. It would be helpful for services to have a list of recommended standardised and psychometric evaluated tools to be used at baseline and follow-up. Services should also be expected to measure maintenance of progress following discharge using the measures at fixed time points (e.g. 6 months, 12 months, 24 months) and encourage re-referrals for individuals where progress is not maintained.

Summary

In summary, this study has uniquely demonstrated the clear improvement in QoL and HRQoL for individuals with DD, following peripatetic PBS service input. Evidence is also presented on positive behaviour change that for the first time, in PBS research, includes details of statistically reliable and clinically significant changes. The social validity outcomes, important within the PBS model, are also uniquely detailed. Limitations to the existing study are considered with the development of more robust research designs required in natural environments. Recommendations are also made for practice and policy implications.

CHAPTER 6

General Discussion

Challenging behaviours are common in individuals with developmental disabilities (Jones *et al.* 2008; Lundqvist, 2013) and given national concern over prior aversive treatment models, there has been growing interest in Positive Behavioural Support as a framework intervention model (Toogood *et al.* 2015, 2016; Kincaid *et al.* 2016). This has been reflected in components of PBS being mentioned in clinical (NICE, 2015, 2017; Skills for Care, 2014) and government guidelines in the UK (Department of Health 2012a, b, 2013, 2014; Local Government Association and NHS England, 2014; Transforming care and Commissioning Steering Group, 2014). Additionally, PBS quality standards for service and training provision have recently been launched (http://pbsacademy.org.uk/standards-for-services/, 2017). Research into PBS as a framework model remains at the preliminary stage and further studies have been advocated to inform theoretical understanding and applied service development (McLean, Grey & McCraken, 2007; Mckenzie, 2011).

Overview of aims, findings and contributions

The framework model for understanding challenging behaviour (described in Chapter 1) indicates that challenging behaviour is the product of the interaction between biological, developmental and environmental factors (Hastings *et al*. 2013; Allen *et al*. 2013). This thesis attempted to expand knowledge on all areas of the causal framework model (Hastings *et al.* 2013) and in particular to address the lack of research into the effectiveness of the peripatetic PBS model as an intervention framework. The findings of the four research studies are summarised in this discussion and the theoretical implications explored. As the research was designed with the aim of having an applied impact to service design, practical implications are considered, and a number of recommendations for the development of PBS as an approach to challenging behaviour are proposed. I will further explore the methodological limitations present within this thesis, and make suggestions for additional research. My personal reflections on the research process are described in Appendix T.

Summary of findings

i) The prevalence of challenging behaviour, associated factors and exploration of risk indices. The first research study (Chapter 2) was a total population study of adults with ID. There has been a lack of robust studies that have estimated prevalence of challenging behaviour in population samples using psychometrically evaluated tools to assess and classify challenging behaviour. This study revealed a prevalence rate of challenging behaviour of 18.1% which was similar to other population studies that had used classification tools for adults with ID (e.g. Jones *et al*. 2008: 18.7%; Lundqvist, 2013: 18.7%). This would suggest that the prevalence of challenging behaviour is higher than the 10-15% indicated in earlier studies (Emerson *et al*. 2001a). Having accurate prevalence estimates is important for service planning and resource funding.

This total population study also aimed to identify correlates of challenging behaviour. Although some factors have consistently been identified as being associated with challenging behaviour, such as communication impairments and increased severity of ID (Emerson & Bromley, 1995; Emerson *et al.* 2001a; Holden & Gitlesen, 2006; Jones *et al*. 2008), there have been conflicting evidence regarding others. This study was unique in exploring correlates associated with different topographies of challenging behaviour, and the use of relative risk statistics enabled the strength of different associations to be considered. This will help in terms of identifying priority factors to address (i.e. the ones with the greatest relative risks). Whilst communication impairments and severity of ID were associated consistently with all behaviours, there were different sets of other correlates associated with different behaviours. Understanding the ‘vulnerabilities’ of specific behaviours is crucial for its potential to provide a first-level identification of likely risk factors for challenging behaviour. Findings on correlates may highlight populations at risk of developing challenging behaviour, thus it is imperative they are considered in the design of preventative Positive Behavioural Support service models.

For the first time in an ID population sample, research on correlates was extended to examine cumulative risk. Evidence from non-ID populations suggests that behaviour problems are associated with cumulative risk (Rutter, 1979), as opposed to individual risk factors acting independently (Appleyard *et al*. 2005). The potential of developing cumulative risk indices (CRI) to inform longitudinal research and clinical practice was explored. Five different methods of putting together a multiple risk index were proposed and all were significantly related to challenging behaviour, including the potentially service friendly, uniform, additive CRI. CRIs have strong methodological advantages over other approaches such as multiple regression, including the fact that collinearity between factors does not distort estimates (Evans *et al.* 2013). Being able to measure cumulative risk, and understand how variations in cumulative risk may relate to challenging behaviour, is important for the development of preventative Positive Behavioural Support approaches. The aim of the approach was to identify a method of developing a CRI that clinical services will be able to use in the future. These may be useful to predict service need and design interventions for individuals with ID that target multiple risk factors or vulnerabilities. Future longitudinal replication is required to establish predictive validity. Identifying adults with multiple risk factors is likely to identify vulnerable adults who are priority for interventions and addressing multiple rather than singular risks is likely to prove more effective in the prevention of challenging behaviour (Evans *et al*. 2013).

ii) *Prevalence of psychotropic medication use and association with challenging behaviour*. In chapter 3, the focus moved from the vulnerabilities associated with presenting challenging behaviour to the impact. Previous studies have indicated a high prevalence of psychotropic medication use in individuals with ID, often in the absence of psychiatric disorder and associated with challenging behaviour. Previous studies have focused on small, highly selective convenience samples with a limited number of population studies (Sheehan *et al*. 2015). Recent UK population samples (Sheehan *et al.* 2015; Henderson *et al*. 2015) have utilised data sourced from primary care. Given that this data will involve participants in contact with prescribing agents, and given the underestimation of mild ID by GPs (Sheehan *et al.* 2015), previous studies may have overestimated prevalence of psychotropic medication use. The strengths of this study were that participants were a total population sample, drawn from multiple sources; medication was independently coded using the World Health Organisation Anatomic Therapeutic Classification Scheme – WHO ATC, 2014; challenging behaviour was estimated in face-to-face interviews using a psychometrically evaluated classification tool for adults with ID (BPI-S; Rojahn *et al*. 2012) at the same time as current medication data was identified, and there was no missing data.

The study revealed that psychotropic medication use was common, with 39.7% of participants prescribed psychotropic medication and 21.89% antipsychotic medication. Polypharmacy and high doses were common. Multivariate analysis indicated psychotropic medication use was associated with psychiatric diagnosis, challenging behaviour, older age and type of residence. Male gender was additionally associated with antipsychotic medication use. Individuals with challenging behaviour were nearly twice as likely to be prescribed psychotropic medication compared to adults who did not present challenging behaviour, and nearly three times more likely to be prescribed antipsychotic medication.

Psychotropic medication use, although still very common, was lower in this study than other estimates in population studies that used data from primary care sources (e.g. Sheehan et al. 2015: 49%; Henderson et al. 2015: 49.1%). The prevalence of medication use may have been over-estimated in previous studies that have not used a total population ID sample identified from multiple sources. In a county in Norway, adults with ID had a similar prevalence of psychotropic prescribing (37.4%) to the current study (Holden & Gitlesen, 2004). Regional variation could also be explained by differences in prescribing patterns between clinicians. The fact that Jersey has an ID service psychiatrist, with a PBS team to refer to, may account for some reduced prescribing. The data also extended previous research findings by revealing different patterns of association with specific topographies of behaviour. The differences in prescribing patterns associated with the prevalence of specific behaviours, or features associated with them, require further investigation. For example, this may reflect a situation where medication is given in response to the requests of those supporting individuals with specific behaviours. Improving access to PBS services, and targeted drug reduction programmes, are required to reduce prescribing levels of psychotropic drugs for challenging behaviour.

iii) ***Towards data-based clinical decision making for individuals with challenging behaviour*.** The Behavior Problems Inventory - short form (BPI-S) is an informant based rating scale to assess the occurrence and severity of challenging behaviour in individuals with ID. The BPI-S data collected in the total population study enabled robust estimation of factors associated with challenging behaviour (Chapter 2) and associations with prescribing patterns (Chapter 3). The BPI-S has good psychometric properties (Rojahn *et al.* 2012a, b; Mascitelli *et al.* 2015; Bowring *et al.* 2017a / Chapter 2) and is an easy to administer tool. In chapter 4, the aim was to extend the use of this tool in research and clinical practice by providing population reference data, clinically significant cut-off scores and reliable change scores. The data generated would be utilised to assess behaviour change for the final study in the thesis – outcomes from a peripatetic PBS service for children and adults with developmental disabilities (Chapter 5).

The further aim of chapter 4 was to develop the BPI-S for use in clinical practice and research. Clinical teams, such as PBS services, would benefit from such a user friendly, low cost, psychometrically evaluated tool, that would indicate whether behaviour change is meaningful, and interventions have been effective. The data provided in chapter 5 was designed to allow users to appropriately interpret BPI-S results obtained from individual and group assessments, especially over time, and thus facilitate clinical decisions about behaviour change.

The reference data in chapter 4 is supplemented by examples drawn from clinical practice to illustrate how to use the normative data, together with clinical and reliable change criteria for the BPI-S. In this way it was designed to be a very accessible and practical chapter. BPI-S population norms provide a benchmark to assist comparison between studies, to identify how an individual's behaviour problem compares to the general ID population (and thus inform those requiring support or intervention), and allow the estimation of numbers across populations with likely behaviour problems. Normative data could be further useful to PBS services at screening to identify those who meet behavioural criteria for a service, or prioritising case waiting. Clinical cut-off scores and reliable change scores provided, calculated using an approach described by Jacobson and Truax (1991), enable services and practitioners, to evaluate behaviour change in their work utilising the BPI-S as a pre-and-post measure.

The strength of this study was that it was derived from a total population sample and there was no missing data within the 265 completed measures, unlike previous BPI-S analysis (Rojahn *et al.* 2012a, b; Mascitelli *et al.* 2015). Time and resource pressures make behaviour rating scales very helpful for services and practitioners and the reference data provided in this chapter will promote the BPI-S as one such tool in clinical practice.

iv) *Outcomes from a peripatetic Positive Behavioural Support service for children and adults with developmental disabilities*. Chapter 5 examined the impact of PBS as a framework model to improve quality of life and reduce challenging behaviour in individuals with DD. Despite the growing interest in such teams (Toogood *et al.* 2015, 2016), there has been little good quality research into their effectiveness in community settings. Previous studies have been limited by small sample sizes, research designs that are not very robust, measures which are not always psychometrically sound, and a lack of clarity over interventions utilised (Kincaid *et al*. 2002; Carr *et al.* 2002; McLean *et al*. 2005). Studies have also focused predominantly on behaviour change, often presented in terms of the percentage of people who have seen reductions in levels of challenging behaviour, without any indication of how meaningful that change was. There has also been a lack of evaluation of the other aims of PBS, namely the impact on quality of life and social validity outcomes (Kincaid *et al*. 2002; Carr *et al.* 2002; McLean *et al*. 2005).

There are several methodological strengths in this study. The sample size of 85 was larger than previous studies on peripatetic PBS teams. The features of the PBS assessment and intervention process are clearly described (Chapter 5). Functional behaviour assessments were completed in all cases to identify maintaining processes as detailed in the framework model (Hastings *et al*. 2013). The BPI-S was used to measure challenging behaviour at baseline and follow-up, and the clinical cut-off scores and reliable changes scores generated in chapter 4 assisted the analysis of data in this study to consider how statistically meaningful the change was for the first time in a PBS study. QoL (measured by a tool adapted from Kincaid *et al.* 2002), health related QoL (measured using the EQ5D 3L and VAS: Euroqol, 1990) and social validity impacts of PBS input were all collectively evaluated for the first time in a study into a peripatetic PBS team.

This study demonstrated the effectiveness of the peripatetic PBS team model. There was a significant improvement across all dimensions of QoL with a large effect size, with one quarter of participants experiencing reliable change in QoL. There was significant positive change in HRQoL with medium to large effect sizes. There was a statistically significant reduction in challenging behaviour as measured by the BPI-S with a large effect size, with 73% of participants experiencing reliable change in one topography of behaviour as measured by the BPI-S and 62% experiencing clinically significant behaviour change. This was the first study to consider social validity outcomes, and the results add to the evidence on positive lifestyle outcomes following PBS input. The research adds to a preliminary, but growing set of studies into the effectiveness of peripatetic PBS teams, but demonstrates this with clear methodological advantages over previous research.

Theoretical implications

i) Positive Behavioural Support. The prevalence of challenging behaviour appears higher in this, and other, recent population studies that have used psychometrically evaluated tools to classify challenging behaviour in individuals with ID, compared to earlier studies. The prevalence of defined 'challenging behaviour' in this thesis (Chapter 2) was 18.1%, but 58.49% of participants presented with 'problem behaviour' leading to the endorsement of at least one item in the BPI-S (Chapter 4). This indicates that a large number of individuals with ID may benefit from PBS input. The findings from this thesis support the application of PBS as an effective model to address challenging behaviour in individuals with DD. All the PBS intervention plans (described in Chapter 5) were based on functional behavioural assessments. These functional behavioural assessments may be an important part of what makes PBS effective. It will be crucial for services who look to replicate PBS models to invest in recruiting trained staff, or investing in training for existing staff, so they are competent in completing functional behavioural assessments.

This thesis has highlighted the importance for PBS services to tackle all three areas described in the framework for understanding challenging behaviour (Hastings *et al.* 2013). Interventions need to address vulnerability factors associated with challenging behaviour (Chapter 2); there is a need to identify maintaining processes through functional behavioural assessments (as detailed in Chapter 5); and services should target impact factors that affect quality of life, including psychotropic medication use (Chapter 3).

PBS has been reported (Chapter 5) to be effective across the age range, for individuals with a range of ID and autism, and for a range of presenting behaviours with various levels of severity. Stakeholders have been shown in this thesis, not only as agents to support change, but as people who can benefit from increased QoL as part of the process (Gore *et al*. 2013). This will be important in terms of how PBS is promoted to stakeholder groups.

PBS has been described as an application of ABA. There is similarity between PBS and ABA in the data, evidence based approaches; conceptually systematic framework; research methodologies, science of behaviour change; and application to natural settings. PBS stresses the emphasis on quality of life interventions and outcomes, social validity, stakeholder collaboration, and the system wide model (Johnston *et al.* 2006). PBS is based on the non-linear nature of ABA with an emphasis on the constructional approach (Goldiamond, 1974) of teaching new behaviours to make old behaviours redundant.

The peripatetic PBS team model (described in chapter 5) is common within the UK especially in adult services. This community model may benefit from an application of the PBS systems approach seen in school-wide PBS (e.g. Sugai *et al*. 2002) and response to intervention (RTI) models (Fuchs *et al.* 2003) utilised within education. These systems approaches utilise a tiered approach to intervention which could be applied to adult services. The concept of applying system wide PBS across residential, inpatient and geographical areas has been suggested and aided by the PBS Competence Framework (www.PBSacademy.org). This is a document produced in 2015 by a coalition of individuals and organisations promoting the application of PBS in the UK. The Competence Framework is divided into three key areas. 1. Creating high quality care and support environments – ensuring services operate from person centred and quality of life focused approaches. 2. Functional, contextual and skilled based assessments – support is based on function based behaviour assessments. 3. Developing and implementing a Behaviour Support Plan – a detailed plan is described to support individuals which includes skills teaching and data based monitoring. The Competence Framework details tiered levels of competencies across three staff areas – direct contact staff, behaviour specialist/supervisor/managerial, and higher levels behaviour specialist/organisational/consultant. The framework details what each level needs to know and do within a whole system focus on PBS.

Adult based services adapting this PBS system model could consider a tiered approach to intervention. They could also consider aspects of universal screening important within the RTI approach (Fuchs *et al*. 2003). There may be ethical and consent issues with this. However, as part of annual health checks, adults with ID could be screened using a CRI tool (as described in chapter 2) and the BPI-S (chapter 4). The CRI tool may identify vulnerability factors that require support from key professionals. The BPI-S may identify adults who require function based behavioural support.

Screening tools could further identify adults who require support with adaptive or communicative skills and ensure the relevant professional support is in place. A focus on skill teaching is often lacking in adult services and it should be an aspect of training included in PBS courses for direct support staff.

ii) The cumulative risk of vulnerability factors. The findings from the total population study (Chapter 2) indicate that a multi-element response to challenging behaviour is required that takes into account interventions that address vulnerabilities to presenting challenging behaviour. Previous research has identified a number of biological and psycho-social vulnerabilities which appear to increase the likelihood of individuals with ID presenting challenging behaviour. Figure 1 shows the specific factors which were significantly associated with specific topographies of challenging behaviour in this thesis (Chapter 2) increasing our knowledge of specific correlates. Research was extended by presenting relative risk statistics on each correlate. Jersey based services have already commenced work to address the psycho-social vulnerabilities identified in this study, initially targeting communication impairments and low engagement levels.

From a behavioural analytic perspective these ‘vulnerabilities’ can be considered in terms of motivating operations (MO’s). The environmental vulnerabilities described may underpin the motivation for challenging behaviour (McGill, 1999). MO’s are any environmental variable that i) alters the current reinforcing effectiveness of a stimulus, object or event or ii) alters the frequency of behaviour that has been reinforced by the same stimulus, object or event (Michael, 1982). Given that the lack of engagement identified for many adults with ID could be considered a deprived state, this may raise the value of certain reinforcers, such as tangible activity. Individuals with ID may engage in challenging behaviours that previously gained access to tangible reinforcers. One way to address these behaviours is to affect the motivating operation, for example, by improving levels of engagement and non-contingent access to tangible items. Theoretically, altering MO’s should be a viable approach to reducing the occurrence of challenging behaviour in adults at increased psycho-social risk (Emerson & Einfeld, 2011).

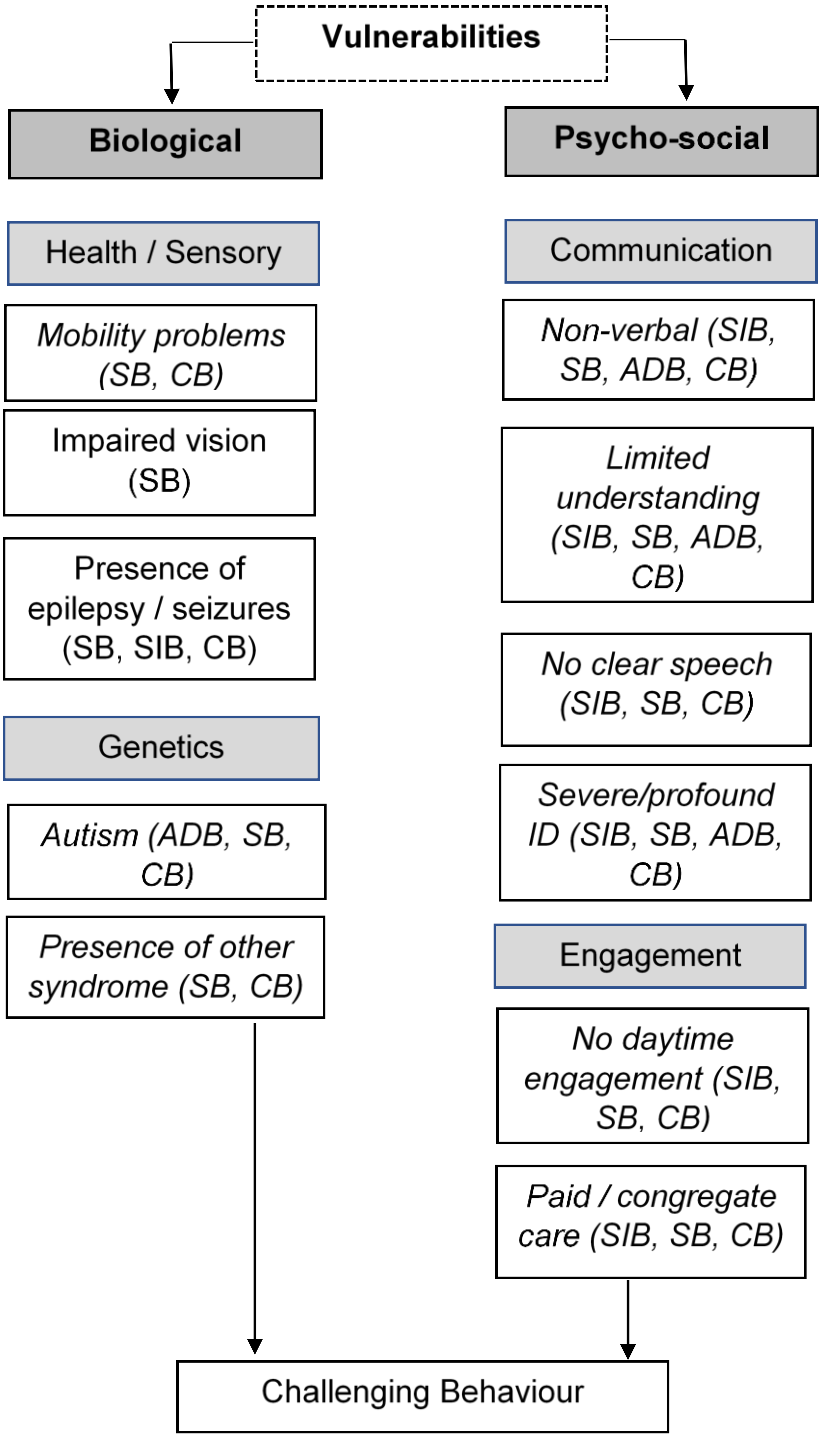

Figure 1. *Vulnerability factors associated with challenging behaviours identified in the total population study in chapter 2 (Category of challenging behaviours associated with: SIB=Self-injurious behaviour; ADB=Aggressive destructive behaviour; SB=Stereotyped behaviour; CB=Challenging behaviour).*

Services who support people with ID need to provide support to address the items listed in Figure 1. Information on correlates of challenging behaviour (Chapter 2) has indicated strategic areas on which Jersey based services should focus. Practical suggestions for focusing on areas like communication and engagement levels will be made later in this chapter.

iii) Cumulative Risk Indices. The cumulative impact of correlates was described in this thesis for the first time in ID literature. Five ways of building exploratory CRIs were described (Chapter 2) and all showed promise in the attempt to create a 'vulnerabilities' risk assessment which carers or practitioners could utilise with adults with ID. Further longitudinal research is already underway to establish the CRIs predictive ability, so that it can be developed into a proactive, practice based tool. There may be ethical and resource implications of identifying adults with ID at risk of presenting challenging behaviour. However, there could be significant applied benefits of such a tool. The uniform, additive CRI could be a simple, low-cost, easy to use tool, subject to establishing its predictive ability. Such a tool would allow practitioners to simply tick which vulnerabilities are present for their focus person. Individuals with higher scores would be more 'at risk' of presenting challenging behaviour and could be prioritised for intervention. This would allow an early intervention approach and fit with the proactive PBS framework model. The tool would also assist the development of an intervention plan by detailing the specific vulnerabilities which require input, and identifying vulnerabilities which may prompt referrals to other services (e.g. communication impairments prompt a referral to Speech and Language Therapy). This would ensure that adults with ID have holistic, robust, multi-disciplinary support arrangements.

iv) Prioritising stereotyped behaviour. Subtypes of challenging behaviour are rarely reported in population samples, where as this was a strength of the population study on prevalence of challenging behaviour (Chapter 2). This revealed that stereotypy was the most prevalent challenging behaviour (10.9%, 95% CI: 7.73%-15.27%). The prevalence of stereotypy has only been considered in one other population study (Lundqvist, 2013: 6.1%). For the first time in the literature, the correlates of stereotypy were identified which included communication impairments, vision and mobility problems, epilepsy and seizures present, living in paid/congregate care, lack of engagement, autism and the presence of another syndrome.

Stereotyped behaviour includes repetitive body movements or repetitive movement of objects. Stereotypy can also be referred to as self-stimulation or ‘stimming’, with the hypothesis that it can serve a positive function for individuals with autism by stimulating one or more of the senses (Cunningham & Schreibman, 2008). One theory is that due to dysfunction within the brain, or hyposensitivity, autistic people crave stimulation and ‘stimming’ serves to arouse the nervous system and release endorphins which create internal pleasure (Kates *et al.* 2005). Another theory is that for people who are hypersensitive, ‘stimming’ is a response to sensory over-load and the behaviour reduces anxiety by blocking out an over stimulating environment (Cunningham & Schreibman, 2008). Research has indicated that some stereotypy can act as self-stimulation or ‘stimming’, and maintain due to automatic reinforcement (Lovaas *et al.* 1987). From this perspective some commentators would suggest that stereotypy may serve some people a helpful function and may not necessarily be ‘challenging’ behaviour.

Yet, despite this perspective, the trends presented in this thesis regarding stereotypy are concerning. Stereotypy was identified as the most prevalent form of challenging behaviour identified in the total population study (Chapter 2). Challenging stereotypy was defined as behaviour occurring at the highest rated frequency, which means 10.9% of participants engaged in stereotypy on an hourly basis. In chapter 5, it was reported that only 3.5% of the people referred to the PBS team had stereotypy mentioned on the referral form as a primary listed behaviour. However, BPI-S data collected at baseline (in Chapter 5) revealed that 74% of people referred to the PBS service scored 1+ on the BPI-S stereotypy scale. This indicates that it is a behaviour which is under-reported to PBS services. In chapter 3, it was revealed that adults with stereotypy were two and a half times more likely to be prescribed antipsychotic medication than adults who did not present stereotypy. This indicates it is a behaviour potentially more prone to pharmacological treatment.

Chronic levels of stereotypy, as per the definition in the total population study, have been correlated with reduced levels of health-related quality of life (Kuhlthau *et al.* 2013). They can also be socially stigmatising, impact on participation in community and educational settings (Kuhlthau *et al.* 2013) and interfere with learning (Koegel & Covert, 1972). A number of studies have also indicated that stereotyped behaviour is a significant predictor of self-injurious behaviour in both people with autism and ID (Barnard- Richman *et al.* 2012; Richards *et al*. 2012; Brak *et al.* 2015). Previous research has suggested that some forms of self-injurious behaviour may evolve from topographically similar forms of stereotypy, such as hand flapping in front of the face evolving into hitting the face (Guess & Carr, 1991; Richman & Lindauer, 2005). In previous research the presence of compulsions has been found to be associated with stereotyped behaviour and self-injurious behaviour (Bodfish *et al*. 1995). Stereotypy has been identified as a risk marker for self-injurious behaviour, and in particular high frequency repetitive or ritualistic behaviour (Oliver *et al.* 2011). In a study of individuals with Cornelia de Lange Syndrome stereotypy predicted clinically significant self-injurious behaviour in all participants (Oliver *et al.* 2009). Given stereotypy is a risk marker for self-injurious behaviour, intervention to prevent the later development of self-injury is indicated (Barnard-Brak *et al*. 2015).

The widespread use of the term ‘stimming’ or self-stimulation to describe these behaviours has been additionally criticised as unhelpful when functional behavioural assessments have not been completed to identify function. Some stereotypy can also be socially maintained (Durand & Carr, 1987; Ahern *et al.* 2003). Guess & Carr (1991) suggest that some forms of stereotypy may initially arise from developmentally delayed, repetitive motor behaviours that are automatically reinforced in under or over stimulating environments, but later become responsive to social contingencies, such as care giver attention. Given the findings reported in this thesis, there needs to be greater focus on referring individuals with high levels of stereotypy to Positive Behaviour Support services. People who present stereotypy have increased risks in terms of increased medication use (Bowring *et al.* 2017b / Chapter 3), restrictions on quality of life (Kuhlthau *et al.* 2013) and development of self-injurious behaviours (Barnard- Richman *et al.* 2012; Richards *et al*. 2012; Brak *et al.* 2015). Functional behavioural assessments are required to understand if stereotypy is maintained by automatic or social factors to guide interventions. Services also need to understand the impact of challenging stereotyped behaviours (as per casual framework, Hastings *et al*. 2013). Considering the impact on quality of life, with stakeholder input, is essential in terms of making person-centred decisions regarding treatment options. This is a potentially difficult area, especially in terms of identifying what is ‘valuable’ for people with autism. However, even if stereotypy does serve a helpful self-stimulatory function, practitioners could further support individuals who are hyposensitive by supporting increased stimulation within the environment. For individuals who are hypersensitive, practitioners could look to identify and remove maladaptive aspects of the environment, in efforts to make the behaviour less necessary.

v) Medication as an impact factor. Psychotropic medication use is still high, and associated with challenging behaviour, despite little evidence of clinical benefit (Emerson & Baines, 2010; Tsiouris 2010; Paton *et al*. 2011; Wilner, 2014). Psychotropic medication can also have a number of adverse side effects such as weight gain, somnolence, metabolic syndromes and behavioural impact (Deb & Unwin 2007; Maher *et al*. 2011; Deb *et al*. 2014; Wilner, 2014; Scheifes *et al.* 2015; Sheehan *et al.* 2017). This thesis extended previous research by revealing that there are different patterns of prescribing for different topographies of behaviour.

High rates of psychotropic medication use are a major issue for people with ID. It should be an area added to the impact list devised by the authors in the causal framework (Hastings *et al*. 2013) as suggested in Figure 2. The side effects described may have a cyclical impact on biological vulnerabilities for challenging behaviour also indicated in Figure 2. Medication reduction should be a priority area for services to tackle.

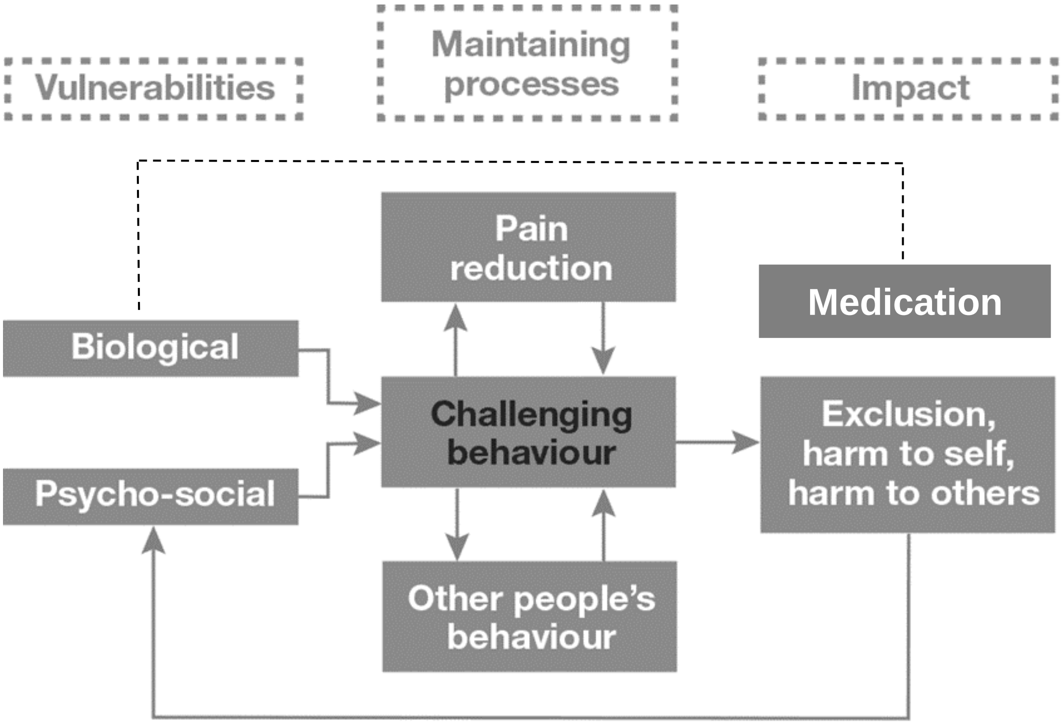

Figure 2. A Framework for understanding why challenging behaviour occurs with medication added to impact factors (Hastings et al. 2013).

Practical implications

PBS is a multi-disciplinary approach: Research on correlates of challenging behaviour indicates the various health and psycho-social responses required. This will involve the input of a number of different professions who work with individuals with ID, who will be tasked with addressing some of the vulnerabilities identified. This research shows that we need behaviour analysts completing functional assessments; nurses and health professionals completing health checks and addressing issues such as incontinence; speech and language therapists working on communication skills; physiotherapists addressing mobility issues; OT's focusing on promoting engagement, teaching independence skills and completing sensory profile assessments; psychologists providing therapeutic interventions; and psychiatrists monitoring mental health and supporting drug reduction programmes. Addressing the vulnerabilities, maintaining processes and impact of challenging behaviour is likely to involve PBS teams centrally, but will require other multi-disciplinary team members.

Improving communication. Improving the ability of individuals with ID to communicate is essential given the clear association between communication impairments and challenging behaviour (Chapter 2). Within chapter 2 the theoretical focus was on correlations between topographies of behaviour and associated factors. There is a role for Behaviour Analysts in interpreting the function of individual's behaviour; the maintaining processes behind specific topographies of behaviour presented. Challenging behaviour may be less likely to occur when a person is understood by others (Allen et al. 2013). Proactively, there needs to be a focus within services to ensure all individuals with ID have access to appropriate methods of communication. Services should ensure that mediators are highly trained in the preferred communication style of that person and that support for communication is seen across all areas of the individual's life (Allen et al. 2013). Communication strategies should be shared across environments, informing partner agencies, through tools like communication passports (Allen et al. 2013). The function of behaviour should be described in PBS plans, with strategies in place to support the communicative function .

In the Jersey population sample, 119 participants had an impairment of expressive communication and 73 had limited understanding of communication, yet only 32 had AAC. Of these 26 used Makaton, but it was not always clear if staff were proficient in its use. In Jersey adult services, the Speech and Language Therapist department only allocate 7.5 hours a week, with one therapist, for adult ID referrals. The investment into this area has clearly been lacking and the above figures are disappointing to services. Efforts have begun to address this, and the results of this thesis have been shared with senior management in the Health and Social Services Department to inform a business case for additional SALT input. The PBS service and Speech and Language Department have always worked closely together, but regular monthly meetings have been introduced to focus on communication promotion in case work. For the individuals identified in chapter 2, a Makaton training programme for mediators began in 2017, and will be extended in 2018. The Behaviour Advisor Assistant from the PBS Team has been tasked with promoting AAC and this is a high priority for the team when addressing vulnerability factors. A commitment to ensure no individual with ID reaches adulthood without AAC, and without skilled mediator support for communication, should be made by H&SS Jersey and other service providers.

Increasing engagement levels. Research presented in this thesis (Chapter 2) has indicated that there was a strong association between a lack of engagement, self-injurious behaviour (RR=3.729) and stereotyped behaviour (RR=2.615). It was revealed that 38.5% of participants had no daytime engagement, similar to previous population estimates (Lowe *et al*. 2007). Challenging behaviour is less likely when people are meaningfully occupied (Allen *et al.* 2013). Services should ensure that mediators provide bespoke support so individuals with ID can participate in preferred meaningful activity that could include domestic, educational, vocational, leisure and social activities (Allen *et al.* 2013).

This thesis indicated that there is a need to increase levels of meaningful engagement for people with ID. Within Jersey there are a number of strategic plans to address this. There has been considerable investment into vocational training to increase the numbers of individuals with ID in employment. During the population study it was discovered that 14% of adults known to services were in employment, which is higher than the UK average of 6% (HSCIC, 2015) and there are efforts to improve this further. H&SS in Jersey are remodelling the day service provision, and the results from this thesis are helping to inform strategic planning regarding day time provision for adults with ID. The PBS team are prioritising addressing engagement levels in case work and in the proactive development of Active Support models (Totsika *et al*. 2011). Active Support focuses on providing support to people with ID to make sure they are engaged and participating in all areas of life. There is some evidence to suggest that Active Support can reduce levels of challenging behaviour (Beadle-

Brown *et al.* 2012). A number of H&SS staff have attended Active Support training programmes to help co-ordinate implementation in their service areas.

Impact on policy and planning in Jersey. Health and Social Services, in Jersey, have a PBS Policy which ensures PBS is systemically supported at the organisational level. Within this the Senior Behaviour Advisor supports the practice leadership of PBS in Jersey. Practice leadership is important for the organisational implementation of PBS (Denne *et al*. 2013). The PBS team also deliver an extensive training programme for care staff to ensure environments are supportive of the values and science of PBS. Results of the research presented in this thesis have been shared through presentations and papers with senior management and members of the multi-disciplinary service in Jersey including MENCAP Jersey, Autism Jersey, and others who provide services for individuals with DD. Results have been included in the PBS training H&SS staff receive in Jersey. Results from the research will aid the design of service planning, training and policy going forward. The aim of the thesis was for it to have an applied impact on services provided in Jersey, and work is planned to ensure that happens. The success of PBS work with individuals with DD described (Chapter 5) has motivated the States of Jersey to extend PBS in other areas, including both education and the children's service.

Promotion of the BPI-S rating tool. The BPI-S is a useful behaviour rating tool for services to use. It could be used by any service, practitioner or researcher involved in behaviour monitoring with people with DD, including commissioners, prescribers, and case managers.

Results in this thesis indicate that services should focus on achieving clinically significant and reliable change in challenging behaviour that can be identified using the BPI-S (Chapter 4). Very few participants in the PBS outcome study (Chapter 5) achieved total extinction of challenging behaviour (10.6%), so this is probably over-ambitious as a service aim. The BPI-S could also be used to monitor maintenance as it could be administered as a regular probe to assess challenging behaviour in case work.

PBS services should make decisions regarding which behaviours to assess using behaviour rating scales such as the BPI-S, which would be subject to less bias than referral forms and provide a more accurate indication of presenting issues. It would appear that referrers are quicker to report outward directed behaviours, such as aggression, that are more likely to affect others in the environment, than inner-directed behaviours, such as stereotypy. Results in chapter 5 also revealed that 50.6% of people referred to the PBS service had items endorsed in all three BPI-S topographies, indicating the multiple behaviours that people with DD present to services. Challenging behaviours identified in the BPI-S could be discussed with stakeholders to consider which ones to target to improve QoL. Individual item behaviours endorsed by the BPI-S would also support PBS practitioners in the operational definitions of presenting behaviours, which is crucial as part of designing data collection tools for functional behavioural assessments.

The BPI-S tool, as well as a version of chapter 4, will be included in future British Institute of Learning Disability (BILD) Centre for the Advancement of Positive Behavioural Support (CAPBS) coaches programmes to promote its use and dissemination in UK practice.

Service models must be evidence-based. Commissioners of PBS services should demand data on behaviour change, quality of life and social validity impacts, to monitor service impact and effectiveness (Inchley Mort *et al*. 2014). Monitoring of outcome data is currently not widespread; it is not routinely required, or sufficiently specified in contractual arrangements (Denne *et al.* 2015). An indicator of good PBS services should be the quality of the outcome data produced. This thesis has described a number of tools which are low cost, easy to administer, accessible and available for services to use. The social validity tool is one example, which had an excellent alpha score of .847 and can be utilised by other services.

Investment is required into peripatetic PBS Teams. PBS services in the UK are currently provided by various organisations that include local authorities, third sector groups and private companies (Toogood *et al*. 2015). Provision of PBS services, demonstrated in this thesis as effective, have to grow to work with individuals who present challenging behaviour and to develop preventative models. Current provision lacks breadth and is small scale (Toogood *et al.* 2015), and this may contribute to higher medication use (Chapter 3) with prescribers feeling pressured to offer an intervention. Given average case length was 45 weeks in the PBS study (Chapter 5), this indicates the need for teams to have the ability to provide intensive, prolonged input. The results of the PBS outcome study (Chapter 5) have informed a business case to expand the PBS service in Jersey.

Supporting Prescribers. High levels of psychotropic medication use in individuals with ID remains an issue despite considerable research and guidance on prescribing (NICE

2015; RCP 2016) and national campaigns such as STOMP - ‘Stopping the over-medication of people with a learning disability, autism or both’ (https://www.vodg.org.uk/campaigns/stompcampaign/). Medication use for challenging behaviour has been proposed as an added impact factor in the framework model (Hastings *et al*. 2013), and should be considered by PBS teams as a further issue, like restrictive practices, to target for reduction. During assessments, PBS teams should document names of psychotropic medication which individuals are prescribed and the reason for prescribing in order to be informed on this issue. Contact should be made with prescribers, and joint working programmes on challenging behaviour devised, with drug reduction included as a target in PBS plans.

PBS teams are in an ideal position to support prescribers by providing behavioural data on the impact of psychotropic medication, be that for new medication or to support drug withdrawal programmes. The BPI-S would also be a helpful tool for prescribers to use to monitor the impact of medication on challenging behaviour, so that any impact of prescribing for challenging behaviour is evidence-based.

The research on psychotropic medication use (Chapter 3) was presented to the psychiatric department, in Jersey, and there is a commitment to reduce psychotropic medication levels in individuals with ID. A number of individuals identified during the data collection (Chapter 3) have received medication reviews and are on drug reduction programmes. A nurse manager in Jersey is currently writing a protocol, based on chapter 3, to oversee psychotropic prescribing and to inform clinic-based reviews. A Learning Disability Nurse sits in all psychiatric appointments for adults with ID, and the protocol will specify tools they can administer, including the BPI-S, to provide clear data to assist prescribers. Psychiatry have committed to refer any individuals reporting challenging behaviour to the PBS Team for input, and these cases will be managed on a joint-working basis. Psychiatry can benefit from the evidenced, data-based approach of behaviour analysis to assess the need and impact of pharmacological interventions on top of subjective discussions with service users and stakeholders. Joint working with PBS teams will be crucial for psychiatrists as an alternative to medication in addressing challenging behaviour. Plans are also in place, in Jersey, to engage with GPs to ensure they are aware of the PBS service.

Information provided in this thesis on medication use in Jersey has been valuable for local services. Other local authorities should conduct audits on medication use in the populations they support to identify adults to prioritise to receive medication reviews.

Methodological limitations in research

This research makes several unique contributions to the literature and there are methodological strengths in all four studies. However, there are also some limitations which should be kept in mind.

In the total population and medication study (Chapters 2 and 3) results only apply to the administratively defined population of adults with ID in Jersey. Other adults with ID, not known to services, were not included in the research. Consideration was given to advertise on the island for participants not known to services, but with timing pressures on the research it was felt to be outside the scope of the study. Future research on total populations should consider making efforts to contact people not known to services. Secondly, the factors listed as correlates (Chapter 2) were those identified as being associated with current challenging behaviour, but they may not have been those conferring risk for the development of challenging behaviour over time. The list of associated factors explored was not exhaustive.

Additionally, in the medication study (Chapter 3) there was a reliance on proxy informants, who were not medically trained, to provide data on medication use as opposed to previous studies where data was received from primary care records. Researchers did make efforts to check medication entries where possible from MAR sheets, the service database, and often asked informants to double check where unsure and followed up for information at a later date.

In chapter 4, there was a level of skewness in the data reported in the BPI-S study, which is common in behaviour rating tools (Rojahn *et al*. 2012). It is unclear how robust the Jacobson and Truax (1991) formula is for non-normally distributed data and how well cut-off scores and reliable change scores are estimated (Evans *et al.* 2013). However, it appears the best option currently to estimate these statistics (Maassen, 2000, 2001).

In the PBS outcome study (Chapter 5), on reflection, it would have been helpful to have recorded data on restrictive practices at baseline, and follow-up, in order to examine change in this key focus area for PBS. Additionally, caution should be taken when services evaluate their own data. The biggest limitation was the lack of a comparison group in the study design, which further studies in community settings should address. The study has additionally not demonstrated maintenance.

Recommendations for future research

Robust PBS study designs. The main priority for additional research is the development of PBS studies that are more robust in terms of the research design. It is difficult to balance the ethics of providing a service in community settings against a robust research programme, but thought needs to be given to the design of such studies. One potential option is to create a wait-list control group, which has been used in other studies where there are ethical implications of denying people access to an intervention (Gallin & Ognibene, 2012). Participants referred to PBS services could be randomly allocated to either the intervention group or the wait-list control group. Those in the wait-list control group would still receive PBS input, but at a later date. This is ethically appropriate as participants are not denied the experimental treatment, and are aware that they are not receiving treatment. Participants in the wait-list control group could still receive input from other members of the multi-disciplinary service to mitigate risks and support carers (e.g. Hassiotis *et al.* 2009). This would further separate generic MDT support from the PBS intervention. Baseline scales could be completed for everyone at point of referral, with the wait-list group acting as the control group to isolate the independent PBS variable. The reality is that most PBS services operate at capacity for case work (Davison *et al*. 2015), and most would operate with a waiting list anyway. The PBS service in Jersey certainly does, and more generally, average waiting times of 6 months have been described in other PBS services (Hassiotis *et al*. 2009). One disadvantage to this model is that the mean time between baseline and follow up measures in the PBS study (Chapter 5) was 45 weeks, so thought would need to be given to ideal waiting times for the control group. Having certain individuals with high risk challenging behaviour wait extended periods for treatment may be unacceptable to health service managers and commissioners who may have a say on waiting list priorities.

A second option would be to consider a multiple baseline design (MBD) which has been widely used in applied behavioural research (Rhoda et al. 2011) and considered a viable alternative to randomised control trails [RCT] (Hawkins et al. 2007). These can be appropriate when looking at how different subjects, with different behaviours, in different settings, respond to one intervention, such as PBS (Baer, Wolf & Risley, 1968; Horner & Baer, 1978). The PBS intervention can be introduced to participants in staggered start times to provide evidence of causal inference (Rhoda et al. 2011), so ethically this is appropriate as no participants are denied the intervention (Rhoda et al. 2011). Baseline measures could be completed for all participants. Participants could initially receive treatment as usual input from the MDT Team (e.g. social work, nursing, occupational therapy, psychology, psychiatry, etc.) for a fixed period of time, such as 4 months; at this time participants could then receive continued input from the MDT plus monthly advice from the PBS Team (referrers get one monthly meeting with Behaviour Advisors who provide intervention advice based on issues discussed at the meeting) for the following 4 months; participants could then receive continued input from the MDT plus full functional behavioural assessments and full PBS service input (as described in Chapter 5). Measures could be completed at baseline, 4 months (following MDT input), 8 months (following MDT plus PBS advice) and 12 months (following MDT input and full PBS input), then 16 months as follow-up. As well as providing control elements, this design would allow some comparison of the impact of the MDT treatment as usual input separate from the PBS input not considered in chapter 5. It would also allow examination of the benefit of a functional behavioural assessment in assisting the design of PBS intervention advice. Further thought needs to be given to unpicking the multi-element nature of PBS input to examine at which point treatment is optimal. Participants also only need wait 4 months for PBS team input, as opposed to 6 months in a previous RCTs (e.g. Hassiotis et al. 2009).

Further PBS evaluation studies should also explore individual case data on challenging behaviour from case files, which services collect as part of case work, to supplement challenging behaviour rating tool data (such as the BPI-S). Having indirect and direct case behaviour data, as well as data from a rating tool, will add to the robustness of conclusions in terms of behaviour change.

Analyses of the impact of the training delivered by the PBS service was not considered (in Chapter 5). There is potential for this to be important in creating a supportive culture in organisations, by promoting staff skills to deliver PBS (Denne *et al*. 2015). Training should be explored in future studies as part of a more rounded analysis of PBS service outcomes. The intensive involvement in individual cases (number of case hours) could also be examined in relation to outcome success, which may inform how services are developed and funded. Studies should compare the cost differential between PBS services and other treatment models, whist evaluating outcome success, which may assist the economic argument for PBS. They should finally explore the barriers to success for some individuals to assist an understanding regarding who may benefit from, currently limited, PBS resources.

Development of the Qol tool. Further research is required on the psychometric properties of the QoL tool used in the PBS evaluation study (Chapter 5) for children/young people and adults. This showed promise as a responsive, pre-post measure. The PBS field requires a user-friendly tool sensitive to QoL outcomes for use in research and clinical practice (Kincaid *et al*. 2002; Townsend-White *et al*. 2011).

The effectiveness of preventative interventions. There is some preliminary research which indicates interventions targeting biological and psycho-social vulnerability factors can have a preventative impact on challenging behaviour. An Active Support study that targeted engagement reduced the severity of challenging behaviour in adults with ID (Beadle-Brown *et al*. 2012); an increase in non-contingent attention reduced challenging behaviour maintained by attention (Carr *et al*. 2009); teaching functional communication training reduced the occurrence of challenging behaviour (Kurtz *et al.* 2011). There are further studies that have addressed vulnerability factors associated with specific conditions, such as autism where activity schedules reduced levels of challenging behaviour in children (Lequia *et al*. 2012). Further longitudinal and intervention studies are required to determine whether modification to the correlates identified prevents future challenging behaviour, especially in adults with ID.

Developing a CRI. Data collection is already underway to repeat the BPI-S total population study on adults with ID in Jersey as part of the longitudinal replication to test the predictive validity of the CRIs (described in Chapter 2). This will identify whether the proposed CRIs predict future challenging behaviour, and which of the five proposed CRIs has the greatest predictive ability. Further research will be required on the clinical utility of a such a tool, and whether interventions that target cumulative risk factors are effective in preventing challenging behaviour in adults with ID.

Stereotypy research. Issues raised in this thesis have raised a number of questions regarding stereotypy in DD which are under researched. Future studies should explore stereotyped challenging behaviour in total population samples, consider impact factors, current treatment models and examining referral rates of stereotypy to challenging behaviour services. If stereotypy is an under-reported challenging behaviour, we need to understand the reasons behind this and examine ways of promoting referrals of stereotypy to PBS teams. Given the potential for some stereotypy to serve a beneficial automatic function in some individuals with DD (Cunningham & Schreibman, 2008), yet also impact on quality of life (Kuhlthau *et al*. 2013), it would be useful to establish protocols to guide PBS service decision making on potential interventions in stereotypy. Future research is also required on the effects of reducing stereotypy as a preventive treatment approach for self-injury (Richman *et al.* 2015).

Medication research. In terms of medication, it was found that general medication use is high in adults with ID (for example, 31.32% were in receipt of medication for the alimentary tract and metabolism, in Chapter 2), and future research needs to investigate the high prevalence of all types of medication prescribed and whether these are indicated by an underlying health need. It was also presented that in Jersey there were less mood stabilisers (2.64% compared to 20%) and less anxiolytics / hypnotics (10.57% compared to 22%) prescribed compared to a previous study in the UK (Sheehan *et al.* 2015). Previous studies (Kiernan *et al*. 1995) have revealed regional variations in prescribing patterns and research should investigate this further to see what can be learnt from lower prescribing areas.

Researchers should also develop studies to evaluate the potential effectiveness of PBS teams working alongside psychiatrists on drug reductions programmes, where psychotropic medication has been prescribed for challenging behaviour. Studies could be designed where some individuals targeted for drug reduction receive psychiatry support and others psychiatry and PBS service input. The BPI-S, and meaningful change statistics provided (Chapter 4), would prove a useful tool to continuously monitor the impact of medication reductions on challenging behaviour, and compare the impact on both groups.

Robustness of BPI-S data. Given the level of skewness described in chapter 5, it is unclear how robust the formulae's given by Jacobson and Truax (1991) are for non-normally distributed data and how well cut-off scores and RC described are estimated (Evans *et al*. 1998). Once further population studies are completed using the BPI-S, one potential solution to this issue will be to pool data and aggregate sample scores between studies (Jacobson & Truax, 1991).

Conclusion

In conclusion, the present thesis demonstrated that the prevalence of challenging behaviour in total population samples is slightly higher than earlier studies suggested. Stereotypy was demonstrated to be the most prevalent challenging behaviour, and has a high association with medication use and a low referral rate to the PBS service. For the first time, the cumulative impact of correlates of challenging behaviour were explored, and these have implications for the design of preventative models for challenging behaviour. Previous studies may have over-estimated psychotropic medication use, but it remains an impact of presenting challenging behaviour for people with ID. Work described on the BPI-S has developed this as an effective, easy to administer tool, with normative and meaningful behavioural change statistics provided that services can use. The thesis highlighted the importance of PBS as a framework model that targets vulnerability, maintaining processes and impact factors for challenging behaviour. PBS was demonstrated to be effective at reducing challenging behaviour, improving quality of life and having wider social validity outcomes for stakeholders. Implications for the field of PBS are described, and it is suggested that good quality services should begin to provide meaningful outcome data to commissioners. Further research has been suggested to increase evidenced-based practice and promote PBS as a framework model to improve quality of life for individuals with DD and their carers.

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APPENDICES

APPENDIX A

PROCESS FOR GAINING PARTICIPANT CONSENT (STUDY ONE)

Process for gaining participant consent.

The prevalence of challenging behaviour in the administrative population of adults with an intellectual disability and / or autism in Jersey.

1. Researcher to identify lead professional for each service user from the FACE database.

2. Researcher to complete **Participant's capacity to consent (Form F1)** with the lead professional to assess each service user's capacity to provide informed consent independently.

3. If the individual is identified as having capacity, the researcher will further assess this by completing the **Protocol for determining capacity to consent in cases where a member of Health and Social Services staff have confirmed the individual's capacity to give or withhold consent (Form F2)**. Information will be provided regarding the research in **Participant information sheet** (**Form F2.1)**.

4. If the service user is identified as not having capacity in **Form F1** the researcher will identify a personal consultee from the FACE database. Under the Mental Capacity Act (2005), when an individual lacks capacity to consent to taking part in a project, the researchers must take reasonable steps to identify a personal consultee. A personal consultee is someone who knows the individual very well. This may be a family member or close friend, but not a paid carer, professional or someone involved in the research study. If a personal consultee cannot be found a nominated consultee will be identified. This will be someone who knows the individual well in a voluntary capacity (e.g. charity / church, etc) or in a paid capacity (e.g. social worker, paid carer, GP). They will not have any connection with the research study. The researcher will then complete **Consent by Proxy (Form F4)** with the personal consultee. Information regarding the research will be provided in **Proxy information sheet (Form F4.1)**.

5. If the service user is assessed as having capacity in **Form F2** and consents to participate in the research, then the researcher will complete **Participant consent form (Form F3)** in the presence of a witness. This will confirm whether the service user gives or withholds consent to participate in the study. Participation in the study involves consent for a named informant to provide information about the service user. Named informants will be adults who know the service users very well and have at least weekly contact with them. They may be family members, carers, keyworkers, job coaches, charity workers, etc.

6. If the service user gives consent in **Forms F2** and **F3**, then the researcher will complete surveys with the identified named informant. If the service user withholds consent in **Form F2** or **Form F3**, then they will not participate in the research.

7. If the personal consultee gives consent in **Form F4**, then the researcher will approach the named informant to proceed with data collection. If the personal consultee withholds consent in **Form F4**, then the service user will not participate in the research.

APPENDIX B

PARTICIPANTS CAPACITY TO CONSENT FORM F1

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Participant Identification Number:

PARTICIPANT'S CAPACITY TO CONSENT (Form F1)
Date: 25th January 2013

The prevalence of challenging behaviour in the administrative population of adults with an intellectual disability and / or autism in Jersey.

A service user who accesses / has accessed your service is being invited to take part in a research project. We would like to assess the capacity of this person to consent for participation to the research study independently. Please indicate whether the service user:

1. Is able to comprehend and retain information material to the decision:

   Yes ☐ No ☐

2. Is able to use and weigh this information in the decision making process:

   Yes ☐ No ☐

If you have answered "No" to one of the above statements, then the service user is judged to lack the capacity to give or withhold consent to the proposed research procedure. Pleased find attached a protocol (Protocol for Capacity Form F2), which the researchers will use if the answers to the questions above are "Yes". This protocol assesses the capacity of the service user to consent to the specific research procedure.

Please read the protocol.

3. Do you think that the service user will be able to complete the procedure described in the protocol?

   Yes ☐ No ☐ Not Sure ☐

If your answers to questions 1 and 2 are "Yes" and to question 3 is "No" or "Not sure", then the researchers will contact the service user's personal or nominated consultee.

Name:..
Signature:...
Date:..
Name of Researcher:..
Signature:...
Date:..

APPENDIX C

PROTOCOL FOR DETERMINING CAPACITY TO CONSENT IN CASES WHERE A MEMBER OF HEALTH AND SOCIAL SERVICES STAFF HAVE CONFIRMED THE INDIVIDUAL’S CAPACITY TO GIVE CONSENT (FORM F2)

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Participant Identification Number:

Protocol for determining capacity to consent in cases where a member of Health and Social Services staff have confirmed the individual's capacity to give or withhold consent (Form F2).

Date: 25th January 2013

1. Read information sheet to participant (Form 2.1).

2. Read the following part of the information sheet: "I am (name) and I work for the Special Needs Service. The Special Needs Service supported you or your carers in the past."

   Ask the participant: "Who do I work for?"
   Score 1 if the participant answers "Special Needs Service".
   Score 0 if the participant gives an incorrect answer.

3. Read the following part of the information sheet: "We would like to find out more about you. We want to understand the skills and needs of people who live in Jersey. We would like to speak to someone who knows you very well (name)..............."

   Ask the participant: "**Why do we want to speak to someone about you**?"
   Score 1 if participant gives answer similar to "find out more about me" or "to find out information about me" or "to understand the skills / needs of people".
   Score 0 if the answer is too vague (e.g. "see me").

4. Read the following part of the information sheet: "We will meet with (name) to ask about your health, where you live, things that you do during the day, your skills, your behaviour".

   Ask the participant: "**What do we want to ask questions about**?"
   Score 1 for any answer similar to "Me" or "my health" or "where I live" or "things that I do during the day" or "my skills" or "my behaviour". Score 0 if the answer is too vague or irrelevant.

5. Read the following part of the information sheet: "We will get information from a lot of people who are supported by the Special Needs Service. We will keep the information safe. Nobody will know we have information from you. We want to ask you if it is OK to ask (name) about you. Remember you do not have to say "Yes". If you do not want us to ask (name) about you, just say "No".

   Ask the participant "**Are you happy for us to speak to......................."**
   Answer "Yes" or "No".
   Ask the participant "**Are you happy for us to ask questions about you and your behaviour?"**
   Answer "Yes" or "No".
   For consent to be given the participant needs to answer yes to both questions.

6. Read the following part of the information sheet: "If you say "Yes" now, but later change your mind that is OK. Just tell us "No" later on. You do not have to say why".

   Ask the participant: "**What will you do if you change your mind?**"
   Score 1 for any answer similar to "Tell you No".
   Score 0 if answer is irrelevant or too vague.

Overall Scoring
If the participant scores 0 to any of the questions under items 2,3,4 or 6, then the participant is assessed as not having the capacity to consent in this specific context and the researchers should follow the alternative route of seeking consent through their personal or nominated consultee. If the participant scores 1 in every question under items 2,3,4 and 6 and answers "Yes" to both questions under item 5, then the participant is assessed as having the capacity to consent and s/he is indicating a wish to participate. If the participant scores 1 in every question under items 2,3,4 and 6 but answers "No" in either question 5, the participant is assessed as having the capacity to consent and is indicating a refusal to participate.

This protocol is based on the procedure followed by Arscott, Dagnan & Kroese, 1998.

Arscott, K., Dagnan, D., & Kroese, B.S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 11(1),* 77-83.

APPENDIX D

PARTICPANT INFORMATION SHEET (FORM F2.1)

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Participant Information Sheet (Form F2.1)

Date: 25th January 2013

Information About You

I am (name) and I work for the Special Needs Service. The Special Needs Service supported you or your carers in the past. We would like to find out more about you. We want to understand the skills and needs of people who live in Jersey.

We would like to speak to someone who knows you very well (name)................

We will meet with (name) to ask about:

- Your health
- Where you live
- Things that you do during the day
- Your skills
- Your behaviour

We will get information from a lot of people who are supported by the Special Needs Service. We will keep the information safe. Nobody will know we have information from you.

We want to ask you if it is OK to ask (name) about you. Remember you do not have to say “Yes”. If you do not want us to ask (name) about you, just say “No”.

If you say “Yes” now, but later change your mind that is OK. Just tell us “No” later on. You do not have to say why.

Thank you for letting us read this to you

APPENDIX E

PARTICPANT CONSENT FORM (FORM F3)

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Participant Identification Number:
Date: 25th January 2013

Participant Consent Form (Form F3)

Information About You

We are interested in finding out some information about you.

To find this out we will need to speak to.................................... who knows you very well.

Are you happy for us to speak to.. about you?

Yes ☐ No ☐

I have witnessed that...has orally consented for researchers to ask.......................................to provide information about them.

Witnessed by (sign):...

Date:...

Name in capitals:...

Address and / or contact number:..

Researchers Name:..

Researcher's signature:...

Date:……………………………………………………………………………………

APPENDIX F

PROXY INFORMATION SHEET (FORM F4.1)

Positive Behaviour Support Team

Admin 1, Overdale, Westmount
Road, St. Helier. JE1 3UH.

Tel: (01534) 445724
d.bowring@health.gov.je

School of Psychology
Bangor University

Adeilad Brigantia, Penrallt Road
Bangor, Gwynedd LL57 2AS

Tel:(01248) 382211 - Fax:(01248) 382599
e-mail: psychology@bangor.ac.uk
www.psychology.bangor.ac.uk

Proxy Information Sheet (Form F4.1)

Date: 25th January 2013

The prevalence of challenging behaviour in the administrative population of adults with an intellectual disability and / or autism in Jersey.

We are a group of researchers from the School of Psychology at Bangor University and the Special Needs Service, Health & Social Services, Jersey. We would like to invite (name) to take part in a new study being conducted by Bangor University, in collaboration with Health and Social Services, Jersey.

What is the purpose of the study?

This individual has previously received a service from the Special Needs Service, Health & Social Services. We are interested in gathering more information about the individuals who have accessed this support. We would like to complete a survey on everybody who has received this service. We would like to speak to (named proxy) who knows (name) very well.

Why am I being contacted?

You have been identified as the personal / nominated consultee to (name). Following investigation, it is has been concluded that (name) is unable to decide for him/herself whether to participate in this research. To help decide if he/she should join the study, we would like to ask you to consent on their behalf. We would ask you to set aside your own views and consider their best interests and what you feel would be their wishes and feelings. Try to identify all the things (name) would take into account if they were making the decision for themselves.

What do I have to do?

If you give or withhold consent after reading the information we provide, we will ask you to indicate this on the Consent Form (F4) on the last page of this information leaflet. We will then give you a copy to keep. If you give consent we will keep you fully informed during the study so you can let us know if you have any concerns. You can withdraw (name) from the study at any time without giving a reason and without the service they receive being affected. If you feel you cannot give your consent, it will not affect the standard of service they receive in anyway. If you are unsure about taking on this role, you may seek independent advice. We will understand if you do not want to take on this responsibility.

Before you decide we would like you to understand why the research is being done and what it will involve. One of our team will go through this information with you and answer any questions you have. We‘d suggest this should take about 10 minutes. Talk to others about the study if you wish.

What does taking part involve?

Our researchers will talk to (named proxy) and complete two surveys about (name). The first survey will collate information regarding (name's) diagnosis, health, communication skills, where they live and what they do. The second survey will ask about their behaviour. The surveys should take about twenty minutes to complete. The whole data collection process should take the research team about six months.

Why should (name) take part?

We cannot promise that this research will help (name), but it may help improve the services for people with special needs. The information gained will assist H&SS understand the needs and thus help allocate resources and plan future services. The information gained may also help researchers understand potential risk markers for challenging behaviour and may help service responses to this in the future.

Confidentiality

Data will be handled in accordance with the UK Data Protection Act (1988) and the Data Protection (Jersey) Law 2005. Only the research team will have access to the completed surveys. You have the right to access the surveys completed on (name) and to check the accuracy of information provided.

All information from the surveys will then be inputted anonymously into a database, using a coding system, and analysed statistically. The results will assist the Special Needs Service in understanding service demand and planning future services. The information may also be used anonymously as part of a PhD research project and may be published.

The surveys will then be stored in the participants file at Overdale as per H&SS protocol. You may withdraw consent at any time during the data collection period. Any data collected will not then be used in this research project. If you would like to withdraw please contact Darren Bowring - Overdale, Westmount Road, JE13UH; Tel- 01534445724; email – d.bowring@health.gov.je.

Risks in taking part

We will be completing the surveys with proxies - people who know the service users very well. We do not believe that this will cause any risks or distress to the individuals themselves. We believe that the potential benefits of this research outweigh the inconvenience placed on proxies who will be asked to complete the short survey with the support of a member of the research team. However, if you have any concerns relating to an adult supported by the Special Needs Service you can contact Steve McVay, Special Needs Service Manager, on telephone: 01534 445166 or email: s.mcvay@health.gov.je.

At the end of the study

You will receive a summary of the study’s findings. We will also publish our findings in places where you and other people can access them: e.g., newsletters (Grapevine) and voluntary organization websites (Jersey Mencap and Autism Jersey).

Research Team

Darren Bowring (PhD Researcher)
Dr Vasiliki Totsika (Lecturer in Psychology)
Prof. Richard Hastings (Professor of Psychology)
Dr Sandy Toogood (Lecturer in Psychology)
Doc Snook (H&SS)
Ashley Kaye (H&SS)
Michael Sleath (H&SS)
Jessica Ramos de Castro (H&SS)

Any concerns or queries?

For any questions about the research, please do not hesitate to contact Darren Bowring on telephone: 01534 445724 or email d.bowring@health.gov.je

Complaints

If you have any complaints about the way this research is being conducted you are welcome to address unresolved concerns to:

Mr Hefin Francis,
School manager,
School of Psychology,
Bangor University,
Brigantia Building,
Penrallt Road,
Bangor,
Gwynedd.
LL58 2AS

APPENDIX G

CONSENT BY PROXY (FORM F4)

Positive Behaviour Support Team

Admin 1, Overdale, Westmount
Road, St Helier. JE1 3UH.

Tel: (01534) 445724
e-mail: d.bowring@health.gov.je

School of Psychology
Bangor University

Adeilad Brigantia, Penrallt Road
Bangor, Gwynedd LL57 2AS

Tel:(01248) 382211 - Fax:(01248) 382599
e-mail: psychology@bangor.ac.uk
www.psychology.bangor.ac.uk

Participant Identification Number:

Consent by Proxy (Form F4)

Date: 25th January 2013

The prevalence of challenging behaviour in the administrative population of adults with an intellectual disability and / or autism in Jersey.

Researcher: Darren Bowring.

You have been identified as the personal / nominated consultee of participant number:...........................

I have been consulted about (name of potential participant) participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved and give my consent.

Yes ☐ No ☐

I understand that I can withdraw him/her from the study at any time, without giving any reason and without the service they receive or their legal rights being affected.

Yes ☐ No ☐

I understand that relevant sections of data collected during the study may be looked at by responsible individuals from Health & Social Services where it is relevant to their taking part in this research.

Yes ☐ No ☐

Name..................................... Date...............................Signature..

Relationship to Participant..

Person undertaking consultation..................................Date................Signature...................
(If different to researcher)

Researcher...Date.........................Signature....................................

APPENDIX H

INDIVIDUAL AND DEMOGRAPHIC SURVEY

Participant Identification Number:
Proxy name:

Date of completion:
Researcher name:

1.	**Date of Birth**		
2.	**Gender** Male……………………..... Female…………………..	 1 2	
3.	**Current address**		
4.	**Type of residence?** Family carer............ Paid carer................ Congregate care....... Independent living...	 1 2 3 4	
5.	**Marital status** Single……..………………....…. Married / lives with partner.... Separated / divorced........…... Widowed...............................	 1 2 3 4	
6.	**Degree of Intellectual Disability** **No intellectual disability**..................... **Mild** (IQ score of 50-69. Most people with mild learning disability can live independently in ordinary surroundings, though they may need help in coping with family responsibilities, housing and employment, or when under unusual stress). ....…………………...... **Moderate** (IQ score of 35-49. Activities of daily living such as dressing, feeding and attention to hygiene are usually acquired over time but extended activities of daily living such as use of money and road sense generally require support. Similarly, supported employment and supported education are the rule)..………………… **Severe** (IQ score of 20-34. Many people in this group can be helped to look after themselves but only under close supervision and to communicate in a simple way. They may be able to undertake simple tasks and engage in limited social activities, but they need supervision and a clear structure to their lives)................................ **Profound** (IQ score of less than 20. They require help and supervision for even the simplest activities of daily living).…...................…… **Not assessed / cannot say**...	 1 2 3 4 5 6	
7.	**Are the following conditions present?**		
7.1	Down Syndrome? Yes, definite..... Yes, query…..... No................... Don't know…..	 1 2 3 4	
7.2	Autism? Yes, definite… Yes, query…... No.................. Don't know.....	 1 2 3 4	

7.3	Dementia? Yes, definite…. Yes, query…... No.................. Don't know….	 1 2 3 4	
7.4	Other known syndrome? (Specify)		
8.	**How long has the individual been living in this setting? (in years. If less than one year enter 1)**		
9.	**Daytime engagement** Paid Work.......................... Voluntary work .... Vocational training............ Education........................... Day service........................ No daytime occupation.....	 1 2 3 4 5 6	
10.	**Has the individual ever been diagnosed with a Psychiatric disorder (only enter if such a diagnosis has been made by a psychiatrist – do not guess)** Don't know...................................... No psychiatric disorder..................... Depressive illness............................ Other affective disorder.................... Schizophrenia.................................. Psychotic condition (unclassified)... Neurosis... Other (specify)................................	 1 2 3 4 5 6 7 8	
11.	**Hearing** Deaf or almost............ Poor........................... Normal or corrected normal (e.g. wearing hearing aid)......................	 1 2 3	
12.	**Vision** Blind or almost....... Poor........................ Normal or corrected normal (e.g. wearing glasses)...................	 1 2 3	
13.	**Speech** Never speaks a word.......................... Uses a few words only........................ Speaks using sentences and normal.... Can talk but does not speak................	 1 2 3 4	
14.	**If this person speaks in sentences is his / her speech...** Difficult to understand even by acquaintances, impossible for strangers......... Easily understood for acquaintances, difficult for strangers....... Clear enough to be understood by anyone......	 1 2 3	
15.	**Does this person communicate in another format? (e.g. BSL, Makaton, etc)**		

	Yes (specify).....................	1	
	No....................................	2	
16.	**Understanding communication (circle the highest number that applies only)**		
	Understands little or nothing............	1	
	Understands a few simple commands (e.g. come here, sit down)...........	2	
	Understands a fair range of instructions or questions related to practical needs........	3	
	Understands comments, questions, instructions related to personal needs and experiences (e.g. did you enjoy the trip to the zoo?)...............	4	
	Understands information about things outside own immediate experiences (e.g. stories or accounts of other people's experiences)...........	5	
17.	**Continence**		
	Doubly incontinent........	1	
	Incontinent (soiling or wetting) once a week or more.........	2	
	Sometimes incontinent but less often than once a week............	3	
	Usually fully continent...........	4	
18.	**Does the person suffer from seizures?**		
	No (no medication, no seizures)...........	1	
	No (controlled by medication).............	2	
	Occasional seizures (less often than monthly).......	3	
	One or more seizures per month......	4	
19.	**Does the person have a diagnosis of epilepsy?**		
	Yes, definite............	1	
	Yes, query................	2	
	No...........................	3	
	Don't know.............	4	
20.	**Current physical health** **poor** **fair** **good** **very good** **excellent**		
21.	**Current medication (please specify name and dose)**		
22.	**Mobility (please indicate which best applies)**		
	Walks by self indoors, upstairs and outdoors............	1	
	Walks by self indoors and up stairs only......	2	
	Walks by self indoors only, no stairs.....	3	
	Mobile with aid or wheelchair indoors, upstairs and outdoors......	4	
	Mobile with aid or wheelchair indoors and upstairs only...........	5	
	Mobile with aid or wheelchair indoors only, no stairs……..	6	
	Gets around with human aid only.......	7	

Questions 13 and 14 are taken from The Wessex Scale (Kushik, Bludon & Cox, 1973).

Questions 1, 2, 8, 16, 17, 18 and 19 are taken from the Individual Schedule of the Challenging Behaviour Survey (Alborz et al, 1994).

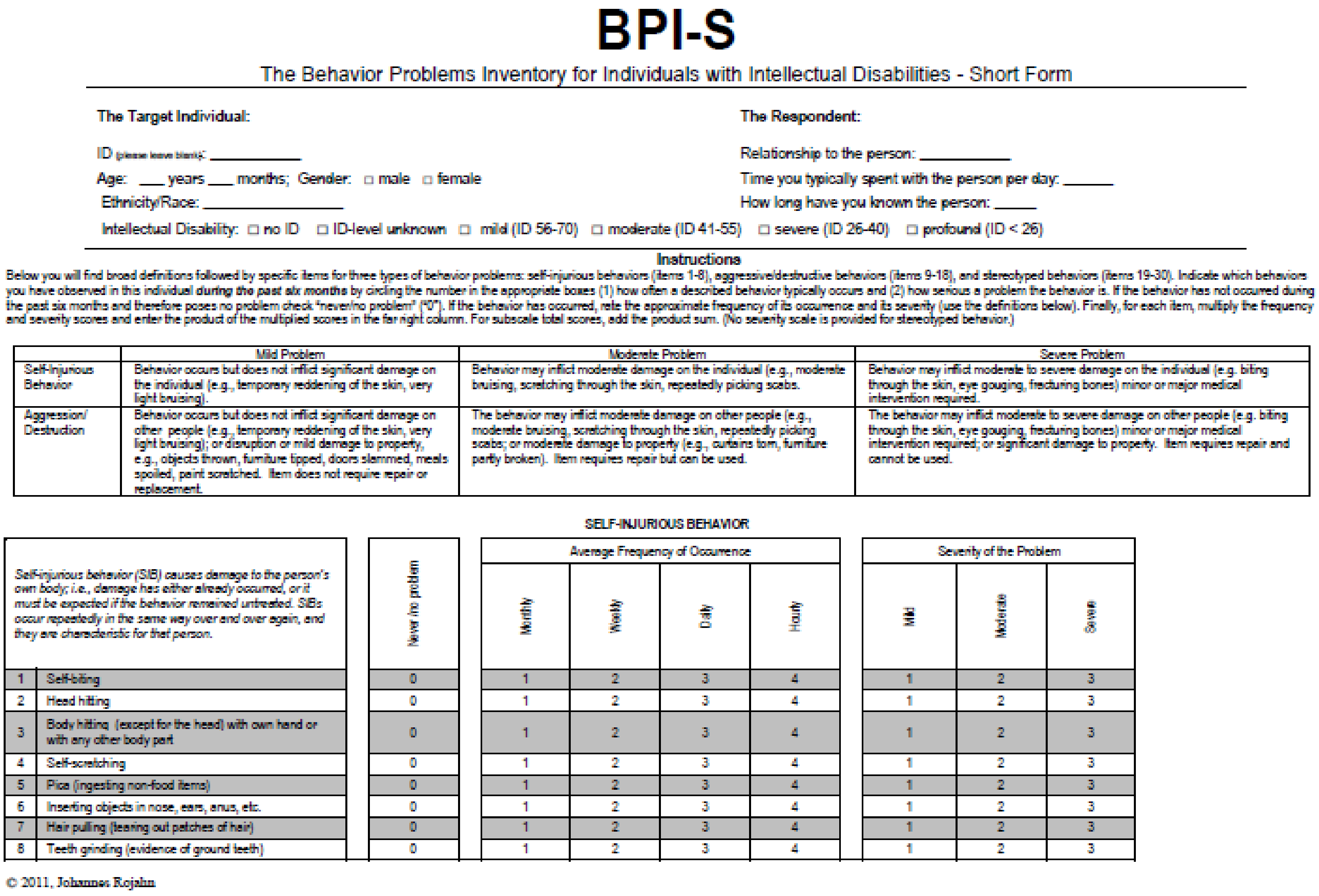
Questions 5, 7 and10 are adapted from the Individual Schedule of the Challenging Behaviour Survey (Alborz et al, 1994).

Question 22 is adapted from The Wessex Scale (Kushik, Bludon & Cox, 1973) including elements of the Individual Schedule of the Challenging Behaviour Survey (Alborz et al, 1994).

Definitions for intellectual disabilities in question 6 are taken from the Department for Work & Pensions (http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/a-z-of-medical-conditions/learning-disability/clinical-features/).

APPENDIX I

BEHAVIOUR PROBLEMS INVENTORY – SHORT FORM



BPI-S

The Behavior Problems Inventory for Individuals with Intellectual Disabilities - Short Form

The Target Individual:

ID (please leave blank): ___________
Age: ___ years ___ months; Gender: ☐ male ☐ female
Ethnicity/Race: ________________
Intellectual Disability: ☐ no ID ☐ ID-level unknown ☐ mild (ID 56-70) ☐ moderate (ID 41-55) ☐ severe (ID 26-40) ☐ profound (ID < 26)

The Respondent:

Relationship to the person: ___________
Time you typically spent with the person per day: ______
How long have you known the person: _____

Instructions

Below you will find broad definitions followed by specific items for three types of behavior problems: self-injurious behaviors (items 1-8), aggressive/destructive behaviors (items 9-18), and stereotyped behaviors (items 19-30). Indicate which behaviors you have observed in this individual ***during the past six months*** by circling the number in the appropriate boxes (1) how often a described behavior typically occurs and (2) how serious a problem the behavior is. If the behavior has not occurred during the past six months and therefore poses no problem check "never/no problem" ("0"). If the behavior has occurred, rate the approximate frequency of its occurrence and its severity (use the definitions below). Finally, for each item, multiply the frequency and severity scores and enter the product of the multiplied scores in the far right column. For subscale total scores, add the product sum. (No severity scale is provided for stereotyped behavior.)

	Mild Problem	Moderate Problem	Severe Problem
Self-Injurious Behavior	Behavior occurs but does not inflict significant damage on the individual (e.g., temporary reddening of the skin, very light bruising).	Behavior may inflict moderate damage on the individual (e.g., moderate bruising, scratching through the skin, repeatedly picking scabs.	Behavior may inflict moderate to severe damage on the individual (e.g. biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required.
Aggression/ Destruction	Behavior occurs but does not inflict significant damage on other people (e.g., temporary reddening of the skin, very light bruising); or disruption or mild damage to property, e.g., objects thrown, furniture tipped, doors slammed, meals spoiled, paint scratched. Item does not require repair or replacement.	The behavior may inflict moderate damage on other people (e.g., moderate bruising, scratching through the skin, repeatedly picking scabs; or moderate damage to property (e.g., curtains torn, furniture partly broken). Item requires repair but can be used.	The behavior may inflict moderate to severe damage on other people (e.g. biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required; or significant damage to property. Item requires repair and cannot be used.

SELF-INJURIOUS BEHAVIOR

	Self-injurious behavior (SIB) causes damage to the person's own body; i.e., damage has either already occurred, or it must be expected if the behavior remained untreated. SIBs occur repeatedly in the same way over and over again, and they are characteristic for that person.	Never /no problem	Average Frequency of Occurrence				Severity of the Problem		
			Monthly	Weekly	Daily	Hourly	Mild	Moderate	Severe
1	Self-biting	0	1	2	3	4	1	2	3
2	Head hitting	0	1	2	3	4	1	2	3
3	Body hitting (except for the head) with own hand or with any other body part	0	1	2	3	4	1	2	3
4	Self-scratching	0	1	2	3	4	1	2	3
5	Pica (ingesting non-food items)	0	1	2	3	4	1	2	3
6	Inserting objects in nose, ears, anus, etc.	0	1	2	3	4	1	2	3
7	Hair pulling (tearing out patches of hair)	0	1	2	3	4	1	2	3
8	Teeth grinding (evidence of ground teeth)	0	1	2	3	4	1	2	3

AGGRESSIVE/DESTRUCTIVE BEHAVIOR

Aggressive or destructive behaviors are deliberate overt attacks directed towards other individuals or property.		Never/no problem	Average Frequency of Occurrence				Severity of the Problem		
			Monthly	Weekly	Daily	Hourly	Mild	Moderate	Severe
9	Hitting others	0	1	2	3	4	1	2	3
10	Kicking others	0	1	2	3	4	1	2	3
11	Pushing others	0	1	2	3	4	1	2	3
12	Biting others	0	1	2	3	4	1	2	3
13	Grabbing and pulling others	0	1	2	3	4	1	2	3
14	Scratching others	0	1	2	3	4	1	2	3
15	Pinching others	0	1	2	3	4	1	2	3
16	Verbally abusive with others	0	1	2	3	4	1	2	3
17	Destroying things (e.g., rips clothes, throws chairs, smashes tables)	0	1	2	3	4	1	2	3
18	Bullying - being mean or cruel (e.g., grabbing toys or food from others)	0	1	2	3	4	1	2	3

STEREOTYPED BEHAVIOR

Stereotyped behaviors look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do NOT cause physical damage.		Never/no problem	Average Frequency of Occurrence			
			Monthly	Weekly	Daily	Hourly
19	Rocking, repetitive body movements	0	1	2	3	4
20	Sniffing objects, own body	0	1	2	3	4
21	Waving or shaking arms	0	1	2	3	4
22	Manipulating (e.g., twirling, spinning) objects	0	1	2	3	4
23	Repetitive hand and/or finger movements	0	1	2	3	4
24	Yelling and screaming	0	1	2	3	4
25	Pacing, jumping, bouncing, running	0	1	2	3	4
26	Rubbing self	0	1	2	3	4
27	Gazing at hands or objects	0	1	2	3	4
28	Bizarre body postures	0	1	2	3	4
29	Clapping hands	0	1	2	3	4
30	Grimacing	0	1	2	3	4

Total Scores

	Frequency	Severity
SIB		
Aggression		
Stereotypy		

APPENDIX J

CONSENT APPROVAL HEALTH AND SOCIAL SERVICES JERSEY (STUDY ONE)

Health and Social Services Department
Jersey Ethics Committee,
General Hospital, Gloucester Street
St Helier, Jersey, JEI 3QS
Tel: +44 (0)1534 442000
Fax: +44 (0)1534 442886

Mr. Darren Bowring,
Positive Behaviour Support Team,
Special Needs Service,
Admin 1,
Overdale,
Westmount Road,
St. Helier, JEI 301-1.

19th March, 2013

Our ref: MT/PM 19.3.13

Dear Darren,

Project: The prevalence of challenging behaviour in the administrative population of adults with an intellectual disability and/or autism in Jersey

Thank you for your application and for attending the recent meeting of the Ethics Committee to present your research proposal.

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research based on the information provided in the excellent application and your presentation to the Committee.

I would also like to convey the Committee's best wishes for the success of this project.
Yours sincerely

M Turner

Revd Maureen Turner,
Secretary of the Jersey Ethics Committee
direct dial: +44 (0) 1534 442314
email: ma.turner@health.gov.je .

APPENDIX K

CONSENT APPROVAL UNIVERSITY OF BANGOR (STUDY ONE)

Bangor Research Applications
11/02/2013 09:34

Dear Darren,

2013-8485 The prevalence of challenging behaviour in the administrative population of adults with an intellectual disability and / or autism in Jersey

Your research proposal number 2013-8485 has been reviewed by the School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.
.

Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy.

If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.

Yours sincerely

Everil McQuarrie

--

APPENDIX L

CONSENT APPROVAL UNIVERSITY OF BANGOR (STUDY FOUR)

-----Original Message-----
From: Bangor Research Applications [mailto:psse09@bangor.ac.uk]
Sent: 19 March 2013 10:55
To: pspf1d@bangor.ac.uk
Subject: Ethics Application Approved

Dear Darren,

2013-9122 An evaluation of outcome data of a Positive Behaviour Support Service in Jersey.

Your research proposal number 2013-9122 has been reviewed by the School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.
.

Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy.

If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.

Yours sincerely

Everil McQuarrie

--
Rhif Elusen Gofrestredig / Registered Charity No. 1141565

APPENDIX M

CONSENT APPROVAL HEALTH AND SOCIAL SERVICES JERSEY (STUDY FOUR)

From: Maureen Turner
Sent: 01 August 2012 09:17
To: Darren Bowring
Cc: Paul McCabe; Emma-Louise Guegan
Subject: RE: Ethics clarification

Dear Darren,

Your project in its present form, as presented to the Ethics Committee meeting on 18th July does not need approval from the local Ethics Committee - it is seen as service evaluation. You can proceed with the project.

You mentioned that you are completing a research proposal for another study, in which case this may need to be presented to the ethics committee at a later date.

I apologise for any confusion.

On behalf of the Ethics Committee I wish you well in your project.

Regards
Maureen

APPENDIX N

REFERRAL FORM – POSITIVE BEHAVIOURS SUPPORT TEAM, JERSEY

States of Jersey

POSITIVE BEHAVIOUR SUPPORT TEAM
REFERRAL FORM

Thank you for referring to the Positive Behaviour Support Team. Answering the following questions as fully as possible will assist us in dealing with your referral promptly. Before completing, please refer to the Guidance Notes or telephone 445724 / 445726 for further information.

1. Details of person referred

Name	**[Type Name and** Press F11**]**
Date of birth	**[Type Date and** Press F11**]**
Address	**[Type Address and** Press F11.**]**
Parish	**[Enter Text Here and** Press F11**]**
Post code	**[Enter Text Here and** Press F11**]**
Telephone	**[Enter Text Here and** Press F11**]**

2. Diagnosis

Does this person have a diagnosed intellectual disability?	**[Enter Text Here and** Press F11**]**
When was this diagnosed?	**[Type Date and** Press F11**]**
Who confirmed the diagnosis?	**[Type Name and** Press F11**]**
Does this person have a diagnosed Autistic Spectrum Condition?	**[Enter Text Here and** Press F11**]**
When was this diagnosed?	**[Type Date and** Press F11**]**
Who confirmed the diagnosis?	**[Type Name and** Press F11**]**
Other significant medical / physical condition/s: **[Enter Text Here and** Press F11**]**	

3. Referral history

Has this person been referred to PBS Team previously?	**"[Yes / No and Press F11]"**

***If answered yes to the above please complete the section below.**

Summarise previous PBST involvement: **[Enter Text Here and** Press F11**]**
What has prompted a re-referral of this person: **[Enter Text Here and** Press F11**]**

4. Environments

How does the person spend their week?	Name of contact person
Home	**[Type Name and** Press F11**]**
Education	**[Type Name and** Press F11**]**
Respite	**[Type Name and** Press F11**]**
Day provision	**[Type Name and** Press F11**]**
Employment	**[Type Name and** Press F11**]**
Other	**[Type Name and** Press F11**]**
In which environment/s is the challenging behaviour a problem?	

[Enter Text Here and Press F11**]**

5. Professional support

Agency	Name	Report date
Social work	**[Type Name and** Press F11]	**[Type Date and** Press F11**]**
Occupational therapy	**[Type Name and** Press F11]	[Type Date and **Press F11**]
Physiotherapy	**[Type Name and** Press F11]	[Type Date and **Press F11**]
Nursing	**[Type Name and** Press F11]	[Type Date and **Press F11**]
Speech & language therapy	**[Type Name and** Press F11]	[Type Date and **Press F11**]
General practitioner	**[Type Name and** Press F11]	[Type Date and **Press F11**]
Clinical psychology	**[Type Name and** Press F11]	[Type Date and **Press F11**]
Educational psychology	**[Type Name and** Press F11]	[Type Date and **Press F11**]
Mental health	**[Type Name and** Press F11]	[Type Date and **Press F11**]
Other:	**[Type Name and** Press F11]	[Type Date and **Press F11**]

6. Describe the challenging behaviour of concern

[Enter Text Here and Press F11**]**

i. How often does it occur?

[Enter Text Here and Press F11**]**

ii. How long does it last?

[Enter Text Here and Press F11**]**

iii. How does it present a risk to the person and / or others?

[Enter Text Here and Press F11**]**

iv. How does it impact on the person's quality of life?

[Enter Text Here and Press F11**]**

7. What other challenging behaviour does the person present?

[Enter Text Here and Press F11**]**

8. What is the desired primary outcome of this referral?

[Enter Text Here and Press F11**]**

9. Level of service required

***Please see guidance notes for services offered**

Advice on managing challenging behaviour (monthly drop-in-clinic)	**"[Yes / No]"**
Functional behaviour assessment & intervention plan	"[Yes / No]"
Advice regarding service design for person with complex behaviour	"[Yes / No]"
Training: Positive Behaviour Support Level 1 and / or 2	"[Yes / No]"
Training: PBS Level 3 (Physical Intervention) and / or 4	"[Yes / No]"

10. Any further information relevant to this referral

[Enter Text Here and Press F11**]**

11. Consent

***Please see guidance notes**

Have you discussed this referral with the person being referred?	**"[Yes / No]"**
Have they given their consent for this referral?	"[Yes / No]"

Has someone else given consent for this referral on their behalf?		"[Yes / No]"
Name of person giving consent:		
Relationship to person being referred:		
Has consent been given for the PBS team to interview key professionals / family members; complete rating scales; collate indirect behaviour recordings; and complete direct observations?		"[Yes / No]"
Has consent been given for data to be used anonymously, by the PBS Team, to evaluate their service and for research purposes?		"[Yes / No]"

12. Referral agent

Name	**[Type Name and** Press F11**]**
Status (to person)	**[Type Title and** Press F11**]**
Address	**[Type Address and** Press F11.**]**
Parish	**[Enter Text Here and** Press F11**]**
Post code	**[Enter Text Here and** Press F11**]**
Telephone	**[Enter Text Here and** Press F11**]**
Email	**[Enter Text Here and** Press F11**]**
Signature	
Date	**[Type Date and** Press F11**]**

Guidance notes

1. *Details of person referred.*
2. *Diagnosis & other relevant clinical information: state only fully diagnosed conditions and the degree of learning disability. Give details of any other diagnosed medical or physical conditions.*
3. *Referral history: state whether this person has been open to PBST in the past and summarise this involvement and specify what has lead to a re-referral.*
4. *Environments accessed by the person referred: state the name of the contact person relevant to each environment accessed by the individual referred and specify only environments in which the challenging behaviour is a problem.*
5. *Professional support / agencies: state name and contact number of professionals with an active involvement. Specify report dates of ANY professional / agency whether they have active involvement or not.*
6. *Nature of challenging behaviour: Describe in detail the exact nature of the challenging behaviour. Points i – iv: specify the frequency, duration, the risk to the person and others and the effect the challenging behaviour has on the individuals quality of life.*
7. *Secondary challenging behaviour: Describe in detail the exact nature of the challenging behaviour.*
8. *Aim of the referral: detail what outcomes are hoped will be achieved by referring to PBST.*
9. ***Advice on managing challenging behaviour (monthly drop-in-clinic):** clinics are conducted on the last Thursday of every month. Appointments are 1 hour and arranged in advance. The aim is provide generic behaviour advice based on the information presented during the appointment. Following each appointment the attendee will receive written follow up summarising the discussion on problem behaviours and any advice given.*

   ***Functional behaviour assessment and intervention plan:** this is a detailed undertaking assessing the function of the challenging behaviour (possibly in multiple environments) providing a written report with an intervention plan. This will involve collating key data regarding the behaviour of concern. This may require interviews with key carers / professionals; completion of rating scales; indirect behavioural recording; direct observations. Data will be analysed and appropriate interventions recommended within a detailed report.*

   ***Advice regarding service design for a person with complex behaviour:** PBST will contribute to a multi-disciplinary team (core group) advising on service design for complex individuals. This does not involve any assessment or training.*

Training in Positive Behaviour Support: *Level 1 and level 2 training courses are offered separately. Each course caters for a maximum of 14 participants and is one day in duration.*

Training in the use of physical intervention strategies: *This is a BILD accredited 2 day course led by MAYBO accredited instructors. It caters for a maximum of 14 participants. Once trained participants are required to attend an "annual refresher" to maintain certification. The SNS has trained Link Workers who will ensure that staff have regular practice and where applicable complete incident debriefs. Bespoke training on individual client need may also be provided.*

N.B. The level of service delivered by PBST will be discussed and agreed in writing.

10. *Any further information: state anything you feel will help us to process the referral quickly.*
11. Consent: Seeking consent is part of a respectful relationship with people with developmental disorders. It is a process, not a one off event, and consent can be withdrawn at any time. Referrers should gain consent from a parent / carer for referrals of children. Referrers should attempt to gain consent from the individual themselves for referrals of adults. If there are capacity issues referrers should seek advice in terms of assessing this and following guidance as detailed in the Mental Capacity Act 2005. Further information can be sought from the Self-Advocacy Project (Jersey) – 0800888127.
12. *Referral agent: enter details of person making referral. Please sign and date the referral form.*

SHOULD YOU HAVE ANY QUERIES, PLEASE CONTACT DARREN BOWRING OR DOC SNOOK, PBS TEAM, ADMIN 1, OVERDALE, WESTMOUNT ROAD, ST HELIER. JE1 3UH. 445724 / 445726.

APPENDIX O

PBS SOCIAL VALIDITY SURVEY

States of Jersey

Positive Behaviour Support Team
Service Evaluation Form

Person referred

Name:

Address:

Date:

Please tick the boxes below to indicate your satisfaction with the input you received from Positive Behaviour Support Team:

	Very satisfied	Satisfied	No view	Dissatisfied	Very dissatisfied
Overall input					
The assessment stage					
The intervention stage					
Closing the case					

Please use the following scale to rate the statements listed below:

1 Strongly agree
2 Agree
3 Neither agree or disagree
4 Disagree
5 Strongly disagree

About you	**Score**
I know more about challenging behaviour than I previously did	
I am more effective in preventing challenging behaviour occurring	
When challenging behaviour occurs I can manage it more effectively	
Challenging behaviour now stresses me less than it previously did	
I am able to cope better with challenging behaviour than before	
There are fewer injuries/ the environment is damaged less than before	
About X	**Score**
There is less risk of X being excluded from home/community/school/etc.	
X does more activities than s/he used to	
X makes more use of the community than before	
X has more (or improved) relationships with others	
People view X more positively than they did previously	
X is now able to communicate his/her needs more effectively	
X is more independent than s/he was previously	

Additional Comments

Return to: Darren Bowring, Positive Behaviour Support Team, Psychology, Overdale, Westmount Road,
St Helier. JE1 3UH

APPENDIX P

QUALITY OF LIFE EVALUATION - ADULTS

States of Jersey

PBS Team – Quality of Life Evaluation (Adults)

Please rate the following aspects of the individual’s life by circling the appropriate response based on the scale below. Rate each statement based on the individual’s life over the last ***two months***.

		Strongly disagree 1	Disagree 2	Neither agree or disagree 3	Agree 4	Strongly agree 5
1.	The person has lots of chances to express personal choices on a daily basis.	1	2	3	4	5
2.	The person gets on well with people they live with.	1	2	3	4	5
3.	The person is willing to try new tasks or activities.	1	2	3	4	5
4	The person has the chance to interact with people they do not live with at least weekly.	1	2	3	4	5
5.	The person gets on well with other adults such as friends and co-workers.	1	2	3	4	5
6.	The person has good access to local places they enjoy visiting at least weekly.	1	2	3	4	5
7.	The person gets on well with family members.	1	2	3	4	5
8.	The person has good chances to participate in leisure pursuits of their own choice at least weekly.	1	2	3	4	5

Adapted from Kincaid, D., Knoster, T., Harrower, J., Shannon, P., & Bustamante, S. (2002). Measuring the impact of positive behavior support. *Journal of Positive Behavior Interventions*, 4, 2, 109-117.

APPENDIX Q

QUALITY OF LIFE EVALUATION – CHILDREN / YOUNG PEOPLE

States
of Jersey

PBS Team – Quality of Life Evaluation (Children & Young People)

Please rate the following aspects of your child / young person's life by circling the appropriate response based on the scale below. Rate each statement based on the child / young person's life over the last ***two months***.

		Strongly disagree 1	Disagree 2	Neither agree or disagree 3	Agree 4	Strongly agree 5
1.	The child / young person has lots of chances to express personal choices on a daily basis.	1	2	3	4	5
2.	The child / young person gets on well with family members.	1	2	3	4	5
3.	The child / young person is willing to try new tasks or activities.	1	2	3	4	5
4	The child / young person has chances to interact with other children / young people at least weekly.	1	2	3	4	5
5.	The child / young person gets on well with adults in education or care settings.	1	2	3	4	5
6.	The child / young person has good access to local places they enjoy visiting at least weekly.	1	2	3	4	5
7.	The child / young person gets on well with other children / young people.	1	2	3	4	5
8.	The child / young person has chances to participate in leisure pursuits of their own choice at least weekly.	1	2	3	4	5

Adapted from Kincaid, D., Knoster, T., Harrower, J., Shannon, P., & Bustamante, S. (2002). Measuring the impact of positive behavior support. *Journal of Positive Behavior Interventions*, 4, 2, 109-117.

APPENDIX R

EQ-5D 3L AND VAS

Health Questionnaire

English version for the UK

Script for proxy version of the EQ-5D: 1

(asking the proxy to rate how he or she, (i.e. the proxy),
would rate the subject's health)

Proxy version of the EQ-5D: 1

By placing a tick in one box in each group below, please indicate which statement best describes *(insert name of person whose health is being assessed e.g. Mr. Smith's or John's)* health state **today.**

Do not tick more than one box in each group

Mobility

No problems in walking about ☐

Some problems in walking about ☐

Confined to bed ☐

Self-Care

No problems with self-care ☐

Some problems washing or dressing myself ☐

Unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

No problems with performing usual activities ☐

Some problems with performing usual activities ☐

Unable to perform usual activities ☐

Pain/Discomfort

No pain or discomfort ☐

Moderate pain or discomfort ☐

Extreme pain or discomfort ☐

Anxiety/Depression

Not anxious or depressed ☐

Moderately anxious or depressed ☐

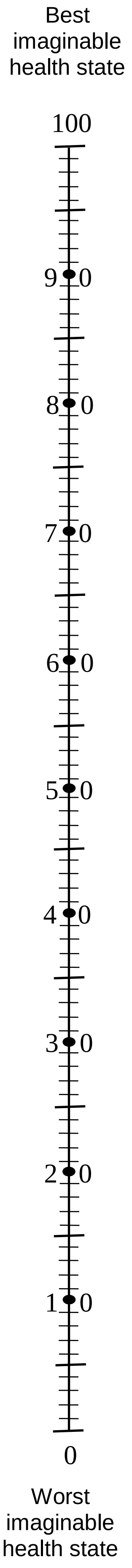
Extremely anxious or depressed ☐

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad the subject's health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad you think the subject's health is today.

(N.B: "The subject's health" may be replaced by e.g. "Mrs. Smith's health")

The subject's own health state today



APPENDIX S

IDENTIFYING A QUALITY OF LIFE TOOL

Quality of Life Measure

One of the aims of chapter 4 was to explore changes in quality of life following the PBS team intervention. Identifying an appropriate quality of life tool was not straightforward. In a systematic review Townsend-White *et al*. (2011) found no specific instruments that measured quality of life in people with intellectual disability and challenging behaviour. A number of tools were considered by the research team including MANS-LD (Skirrow & Perry, 2009), PWI-ID (Cummins & Lau, 2005), PEDS-QOL (www.pedsql.org), QUOLIS (Ouellette-Kuntz, 1990), and WHOQOL-DIS (Power, 2011). All tools were evaluated for purpose against the following criteria (presented in table 1): The rating scale must be suitable for all ages or have child and adult versions; there must be comprehensive subscale / domains assessed by scale; the measure must below effort to administer in terms of number of items and time for completion; the measure must be suitable for varying ability levels of the population; There needs to be various versions available (such as self-report and proxy); the measure must rate subjective and objective QoL; the measure must have adequate Inter-rater reliability; Internal consistency, and test-retest reliability; norms should be available for the target population; the measure should be low cost and responsive as a pre and post intervention measure.

	MANS-LD (Skirrow & Perry, 2009)	**PWI – ID (Cummins & Lau, 2005)**	**PEDS – QOL (www.pedsql.org)**	**QUOLIS – (Ouellette-Kuntz, 1990)**	**WHOQOL – DIS (Power, 2011)**
Age range for target population	18 +	18+ (school age scale available PWI-SC)	Child Self-Report Ages 5-7, 8-12, 13-18; Parent Proxy-Report Ages 2-4, 5-7, 8-12, 13-18	18+	18+
Subscale / domains assessed by scale	5 domains + WHOQoL 8	7 domains	4 domains	12 domains	4 domains

No of items	19	8 plus pre-test	23	43	13 (plus 26 WHOQoL Bref)
Time for completion	20-40 minutes	10-20 mins (Cummins & Lau, 2005) 45 minutes (Townsend-White, et al, 2011)	4 minutes	N/A	20 – 30 minutes
Versions available (Self-report, proxy, both)	Self-report with support.	Self	Self and a parent proxy version	A proxy measure that features ‘residential satisfaction scale’ verbal clients can complete	Both
Measures subjective or objective QoL	Subjective	Subjective	Subjective / objective	Subjective / objective	Subjective / objective
Inter-rater reliability	N/A	Good 0.76 (McGillivray, 2009)	Total Scale Score: 0.88 Child Self-Report; 0.90 Parent Proxy-Report	Good, above 0.60.	N/A
Internal consis-tency	N/A	Good (McGillivray, 2009)	Internal consistency reliability of the PedsQL was excellent, with alphas for the generic core scales in both self- and proxy-report greater than the 0.70 standard	Fair (with exceptions on 3 domains)	Cronbach Alpha value of 0.808 for ID group
Test-retest reliability	N/A	0.58 (McGillivray, 2009)	Good. test-retest reliability (PedsQL r range, .75-.90. McCarthy et al, 2005).	N/A	N/A
Are norms available for target population ?	NO	Australian norms are available	Population norms available	N/A	WHOQoL-Dis field trial provides preliminary reference data.
Level of ID for target population	Initial studies trialled	Mild / moderate	All population	Mild/moderate/severe/profound	Self – mild / moderate; proxy –

	with Mild – severe ID and Aspergers				severe - profound
Cost	Free	Free – with authors permission	Free for non-funded research	Free, but two day training course to administer	Permission required from WHO

Table 1. Comparison of QoL tools

As suggested in previous research (Townsend White *et al*. 2011) none of the measures were ideal. Measures varied considerably in terms of the domains of quality of life they assessed. It is generally agreed that there are eight domains of quality of life (Schalock *et al*. 2002: Emotional wellbeing, interpersonal relationships, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion, rights) and some tools (e.g WHOQOL-DIS) measured only a small number of domains. The length of some tools was substantial (e.g. MANS-LD, QUOLIS), some had no validity or reliability scores (e.g. MANS-LD), some had no proxy version (e.g. PWI-ID), some were child only (e.g. PEDS-QOL) or adult only (e.g. PWI-ID) and some required a training course prior to application (e.g. QUOLIS).

References:

Cummins, R.A. & Lau, A.L.D. (2005). *Personal Wellbeing Index (English) – Intellectual Disability (*3rd Edition). Deakin University.

Power, M. (2011). *WHOQOL-DISABILITIES Module Manual*. WHO.

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., et al. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation,* 40, 457–470.

Skirrow, P. & Perry, E. (2011). *The Maslow Assessment of Needs Scales (MANS).* Mersey Care NHS Trust.

Ouellette-Kuntz H. (1990) A pilot study in the use of the Quality of Life Interview Schedule. *Social Indicators Research*, 23, 283–98.

APPENDIX T

PERSONAL REFLECTIONS

Personal reflections

My entire career has been dedicated to working with individuals with challenging behaviour. Following my undergraduate degree I undertook voluntary placements working with an educational charity for children from developing countries, then with children affiliated to gangs in the USA. I then spent ten years working as Head of Child Care at a charitable school for boys with Social, Emotional and Behavioural difficulties (SEBD) in the UK. Whilst working I completed an Advanced Certificate in Emotional and Behavioural Difficulties and a Master’s Degree, in Education, in Emotional and Behavioural Difficulties. Whilst we did not describe the approach as Positive Behavioural Support the school very much worked under this ethos and this provided me with the value base and approach which has since guided my work.

For the last 14 years I have been Senior Behaviour Advisor, Positive Behaviour Support Team, Jersey. Upon commencing this role I completed a second Master’s degree in Applied Behaviour Analysis (ABA). In 2011, I was extremely fortunate to have the chance of undertaking a PhD. I believe that undertaking academic and research based work, whilst engaged in work in community settings is valuable. The research described in this thesis has aided my role by not only increasing my knowledge on the subject matter, but the research results are having a major impact on applied practice in Jersey. Being able to examine the research results, then immediately work on how they impact into practice has been incredibly rewarding and satisfying. It was the main aim of the thesis that the research would have an applied benefit for services and the people that use them in Jersey. Working full time and undertaking research has been an endeavour, but one that works well and I have thoroughly enjoyed it.

I have attempted to disseminate the research in various ways in Jersey, through training programmes, attending team meetings, presentations, and at conferences. I have presented the research (chapters 2 and 3) at several conferences in the UK including the 2017 British Institute of Learning Disabilities (BILD) international PBS conference. Through my additional role as PBS Consultant for BILD, I have disseminated research outcomes at training events and national PBS coaches summits. I have also included results in training courses I have designed and delivered for BILD.

One of the aims of the thesis was to achieve strong methodological advances in each of the studies. Developing my skills in statistics was initially made harder by completing the research by distance, as I could not attend the Advanced Statistics course lectures or workshops at the University. I had to teach myself and complete the weekly examinations online, and attend Bangor for the formal examinations. The extra effort I went to at this stage has really benefitted my skills in this area. I have really developed as a researcher in my proficiency in using SPSS and the various statistical approaches considered during the studies.

I intend to continue with research, with data collection already underway to continue to develop the work on Cumulative Risk Indices (described in chapter 2). I also intend to continue to promote the application of academic research into practice to improve service outcomes for people with developmental disabilities and their carers.