**Professional carer experiences of implementing Positive Behaviour Support for adults with Intellectual Disabilities**

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June 2019

*Research submitted in partial fulfilment of the requirements for the degree of Doctor in Clinical Psychology (DClinPsy), Royal Holloway, University of London*

**Acknowledgements**

Firstly, I would like to thank my project supervisors, Dr Kate Theodore, Dr Karen Dodd and Dr Ines Mendes, for their continued help and support throughout this project and Alex Sharpington for assisting with the systematic review. Their support and guidance was invaluable to the process and I really appreciate all the time and effort they dedicated to helping me throughout this journey.

I would also like to thank all the participants for taking the time to be involved with this project, as it would not have been possible without them, and the home managers for agreeing to the project and supporting the recruitment process.

Finally, I am extremely grateful for the support provided by my friends and family throughout this project and the course of training, and want to give a big thank you to my husband, for keeping me smiling throughout. I couldn’t have done it without you.

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# Executive Summary

The purpose of this thesis was to conduct a systematic review of the evidence base for Positive Behaviour Support (PBS) when implemented with adults with intellectual disabilities (ID) in social care settings. Following this, the empirical project aimed to explore the processes experienced by care staff when implementing PBS with this same population. Following this executive summary, the thesis is divided into three sections; systematic review, empirical project and an integration, impact and dissemination section.

## Background Information

Research suggests that individuals with ID are at a higher risk of displaying challenging behaviour compared to the general population, and as a result experience detrimental consequences to their quality of life and wellbeing. Challenging behaviour is seen as a barrier to inclusion, interferes with social relationships, limits opportunities for independence and increases risk of abuse and physical or chemical restraint. Therefore, reduction of challenging behaviour is seen as a priority for individuals with ID and challenging behaviour. Consequentially, professional guidelines and policy have drawn on the principles of Positive Behaviour Support (PBS) and recommended it as a framework for supporting individuals with challenging behaviour.

PBS is an evidenced based, person centred framework that aims to improve the quality of a person’s life by promoting inclusion, choice, participation and opportunity. PBS has been shown to be an effective approach for supporting individuals with challenging behaviour, by reducing the need for restrictive practices and increasing positive behaviours. It combines behavioural intervention with person centred values, whilst emphasising inclusion, participation, respect, positive interactions and skill development. It comprises a comprehensive functional assessment of the behaviour and an individualised behaviour support plan, which includes ecological strategies, skill development, focused support and reactive strategies.

## Systematic Review

### *Aim*

The existing evidence base for PBS spans across many settings and populations. Reviews conducted into the effectiveness of PBS so far have looked at the efficacy of PBS generally, focused on single components of PBS or are now grossly outdated. In addition, previous reviews included a range of ages, including children, were across a range of settings or focused primarily on managing severe and high rate challenging behaviours only. To date there has not been a review looking specifically into the use of the PBS framework in community settings for adults with ID. As PBS is recommended as best practice for this population, a review of the literature looking at its effectiveness with this population specifically could give weight to this recommendation and provide insights into the existing evidence base.

### *Method*

A search of PsychInfo and PubMed databases was conducted in order to identify relevant studies investigating the effectiveness of PBS with adults with ID. Exclusion and inclusion criteria were applied to the search results and seventeen studies were identified as being appropriate for this review. All studies were assessed for their methodological quality using the Quality Assessment Tool for Quantitative Studies. An adapted version of this tool was used for studies of single case design, in order to assess components specific to this research design. Where treatment effects were not reported in terms of statistical significance, Points of Non-overlapping Data (PND) was calculated in order to provide a comparable outcome metric. Reliability checks were conducted throughout by a research assistant, in order to control for bias. A narrative synthesis of the data was described due to the heterogeneity of the included studies.

### *Results*

Seventeen studies met the inclusion criteria for this review. Eleven of these were single case study designs, four were Randomised Control Trials (RCTs), one was a non-randomised control trial and one was a service evaluation. Thirteen of the identified studies provided statistical data in support to PBS as an effective intervention for reducing challenging behaviour. It was not possible to calculate effect sizes for three studies but all reported a reduction in challenging behaviour post implementation of PBS. One study found no significant difference. Findings of the effect of PBS on quality of life were varied.

The methodological quality of the studies was generally low. Only six studies were rated as moderate overall and none were considered to have strong methodological quality. The blinding and intervention fidelity domains of the quality assessment tool were the weakest amongst the experimental design studies. Scores on the confounding variables domain were weak for all single case design studies. Intervention fidelity is a particularly important domain for studies involving individualised and variable interventions, such as PBS. Nine of the seventeen studies included did not report a measure of fidelity and the only study to find no positive effect of PBS reported poor intervention fidelity, suggesting it was not PBS that was being measured in this instance.

### *Discussion*

This was the first review to show that, despite the substandard quality of research, PBS is effective at reducing challenging behaviour for adults with ID. There is also suggestion that PBS has a positive impact on individuals’ quality of life, although more reliable and appropriate measures of this are needed. Results from this review suggest that PBS should continue to be recommended as best practice. In order to further enhance the quality of the evidence for PBS, future research should prioritise larger scale, controlled studies, exploring intervention fidelity, continuing to expand outcome measures beyond challenging behaviour and including service users in research.

### *Strengths and limitations*

This review is one of the first to look into the use of the PBS framework with adults with ID. The review process was strengthened by the extensive use of reliability checks, assessment of methodological quality and calculation of statistical significance when studies did not report this. The review is limited by the use of two databases, as relevant evidence may have been missed if published in journals not indexed on these sites. The included studies were conducted in only western societies and no consideration was given to the physical and mental health of the included participants. Furthermore, only peer-reviewed articles were included increasing the risk of publication bias in the findings reviewed.

## Empirical Article

### *Rationale*

The systematic review demonstrated that PBS is an effective framework for working with people with ID and challenging behaviour, and PBS is considered best practice in services for this population. Despite this, appropriate use of PBS within ID services is limited. Organisational change is considered a difficult feat and a clearer understanding of processes that influence successful implementation of PBS is required to promote its use in practice and subsequently improve services for adults with ID and challenging behaviour.

Research into the underutilisation of evidence based practice in healthcare emphasises the need to understand difficulties experienced within a specific context. Although existing theories provide some guidance for how to best undertake organisational change generally within healthcare settings, the literature regarding implementation of PBS has primarily focused on children in educational settings. Given that these settings vary considerably to adult social care settings, it is proposed that research exploring implementation of PBS in this specific context is needed. Therefore, this project aims to explore the organisational processes experienced by staff members when implementing PBS within social care settings for adults with ID.

### *Method*

Thirteen staff members were recruited from three social care homes for adults with ID. Interviews were conducted to explore their experiences of implementing PBS in these settings. Interviews were transcribed and analysed using a Grounded Theory approach. Participants and local clinicians were consulted with regarding emerging themes and findings, in order to check reliability and understanding of the developing model.

### *Results and discussion*

Six theoretical codes were identified: (1) being right for the job; (2) having the right tools for the job; (3) being supported; (4) implementing PBS; (5) reinforcing the use of PBS; and (6) taking time. The codes were incorporated into a model which allows for guidance and recommendations to be provided to services for implementing and sustaining the use of PBS.

The majority of the findings were consistent with previous literature relating to implementing evidence based interventions generally and the use of PBS in practice; however the findings of this study are novel in their application to the PBS framework specifically with adults with ID. This study brought these findings together in the development of a model of implementation specifically for this population. Furthermore, the findings of this project are an extension of a previous study by Woolls, Allen and Jenkins (2012) looking at staff views of PBS in practice. A major criticism of this previous study was the affiliation of the researchers with the recruited services, leading to potential bias in the data collected. Although there were many similarities with the current findings, there were also discrepancies in the stressors reported (towards manager and service user characteristics) and whether participants viewed PBS being mandatory as a driver towards implementation or not. These differences may reflect the stage of implementation.

### *Strengths and limitations*

This study was robust in its application of constructivist Grounded Theory methodology and its use of participant involvement strengthens its credibility. In line with theoretical sampling, a range of professionals were recruited and particular roles were targeted in order to check emerging themes. Furthermore, the sample size recruited is deemed sufficient for a Grounded Theory study. The conclusions of this study are limited by the use of only recruiting NHS-run services within a single location of the UK, reducing their generalisability. The services were also considered to be working within a well-established PBS framework, which although meant that facilitating factors were extensively discussed, it may mean that challenges to implementation were overlooked.

## *Conclusions*

Despite the methodological quality of the evidence, the systematic review concludes that PBS is effective in reducing challenging behaviour for adults with ID. Further research is needed to investigate other outcomes intended by PBS, including quality of life, and attention should be given to improving the quality of research in this area.

The empirical article explored the experiences of staff implementing this evidence based approach in practice, in an attempt to gain a better understanding of how to support services to utilise PBS. Although continued investigation is required to further enhance this understanding, the insights provided by this project allow for recommendations to be made in order to support services and consequently, enhance the support their service users receive.

## Integration, Impact and Dissemination

The systematic review looked at reviewing the effectiveness of PBS with adults with ID and challenging behaviour, whilst the empirical project looked at staff experiences of implementing PBS with this population. The systematic review’s finding that generally fidelity to the PBS framework is poor provides further evidence that research into how to best implement and sustain the use of PBS is required. Had the systematic review not shown PBS to be an effective framework, the empirical project may not have been so relevant and necessary to the field.

Research gaps were highlighted by both studies and these include the need for improvements to methodological quality of research, development of reliable and valid measures of quality of life for individuals with ID, identification of effectiveness of specific PBS components and what facilitates their implementation and inclusion of individuals with ID in research. Further exploration of implementation processes in services run by non-NHS providers and with less well-established PBS frameworks within the services would also allow for greater generalisability of the findings. In terms of impact on clinical practice, both studies suggest that PBS should continue to be recommended as best practice for this population. The systematic review showed that intervention fidelity is poor for PBS and the empirical project provides recommendations for how to enhance this.

Findings will be disseminated to the services where recruitment took place and the clinicians that provided consultation on the project. Both pieces of work will be submitted for publication in peer reviewed journals and the empirical project has been submitted for presentation at the International Association for the Scientific Study of Intellectual and Developmental Disabilities World Congress. Finally, findings will be shared with commissioners and policy makers for social care services for adults with ID.

# Chapter 1. A Systematic Review of the Effectiveness of Positive Behaviour Support with Adults with Intellectual Disabilities

## Abstract

Intellectual Disabilities (ID) are a risk factor for displaying challenging behaviour, which is known to be detrimental to an individual’s health and wellbeing. Positive Behaviour Support (PBS) is currently recommended as the best practice framework of intervention for adults with ID that display challenging behaviour. At present, reviews into the effectiveness of PBS have been inclusive of children and adult participants across a range of settings, primarily schools. This review aimed to investigate the effectiveness of PBS with adults with ID in community settings. A search of PsychInfo and PubMed databases was conducted to identify relevant studies investigating the effectiveness of PBS with this population. Additional articles were identified from searching the reference lists of articles included from the database search. Exclusion and inclusion criteria were applied to the search results and seventeen studies were identified as being appropriate for this review. Eleven of these were single case study designs, four were Randomised Control Trials (RCTs), one was a non-RCT and one was a service evaluation. Thirteen of the identified studies provided statistical data in support to PBS as an effective intervention. It was not possible to calculate effect sizes for three studies but all reported a reduction in challenging behaviour post implementation of PBS. One study found no significant difference. The methodological quality of the studies was generally low and limitations of the literature are provided, along with recommendations for further research.

## Introduction

There is a vast body of literature relating to the prevalence, nature and impact of behaviours that challenge for people with intellectual disabilities (IDs; McClintock, Hall & Oliver, 2003). ID is characterised by significant impairment in cognitive and adaptive functioning, which originates during childhood (American Psychiatric Association, 2013). Evidence suggests that there is a much higher risk of displaying challenging behaviour in individuals with ID compared to the general population (Dunlap & Carr, 2007), although prevalence rates vary within the literature. NICE (2015) reported prevalence ranging from 5-15%, and suggests that the more severe an individual’s disability, the more likely they are to display challenging behaviour. Janssen, Schuengel, and Stolk (2002) report the figures to range from 30-60%, whilst 10% of the ID population have been found to be rated as showing “seriously challenging” behaviour (Lowe, Allen, Jones, Brophy, Moore, & James, 2007). Furthermore, people with an ID and communication difficulties, Autism Spectrum Disorder (ASD), sensory differences or physical or mental health problems are also more likely to display challenging behaviour (NICE, 2015).

Challenging behaviour is defined by The Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007, p.88) as the following:

*‘Behaviour can be described as challenging when it is of such an intensity, frequency, or duration as to threaten the quality of life and/or the physical safety of the individual or others and it is likely to lead to responses that are restrictive, aversive or result in exclusion.’*

This definition of challenging behaviour is socially constructed (British Psychological Society & Royal College of Psychiatrists, 2016) and the term itself was initially introduced as a way of suggesting that the person themselves is not inherently challenging, as previously thought, but that the behaviour displayed can pose a challenge to services and those working with the individual. However, over time there has been a shift towards the term ‘challenging behaviour’ obtaining a pejorative meaning and towards it being applied as an inappropriate label for an individual, rather than a description of their behaviour (Department of Health, 2007). As a consequence, clinicians and those working with people who display challenging behaviour are encouraged, and often have a preference, to refer to the concept as ‘behaviours that challenge’ services. However, for the purpose of brevity for this report, the term challenging behaviour is used throughout in the original sense for which it was introduced.

Although prevalence rates vary, there appears to be a consensus in the research that individuals with ID and challenging behaviour experience highly detrimental consequences as a result of their behaviour. Challenging behaviour can significantly diminish the quality of the individual’s life and poses as a stressor and, at times, treatment dilemma to those working with the individual (Janssen et al., 2002). It is seen as a barrier to inclusion, interferes with social relationships and limits opportunities for independence (Odom, Horner, Snell, & Blacher, 2007). Furthermore, the detrimental impact also results from the responses others display towards the individual. Emerson, McGill, and Mansell (1994) report these responses to include increased risk of physical abuse, unnecessary or excessive use of medication, physical restraint, deprivation and neglect. Due to their interference with learning, socialization, community participation and overall quality of life, reduction of challenging behaviour is seen as a priority in service and provision for individuals with ID (Dunlap & Carr, 2007) and it is crucial that effective and appropriate interventions are available for those who show challenging behaviour. Consequently, over the last fifteen years, professional guidelines and policy have drawn on the principles of Positive Behaviour Support (PBS) and recommended it as a framework for supporting individuals with challenging behaviour (Gore et al., 2013).

### Positive Behaviour Support

Applied behavioural science developed as a response to restrictive and punitive interventions for challenging behaviour which were ineffective and inhumane (Dunlap & Carr, 2007). In the 1980s, recognition of the need to understand the function of the behaviour led to a focus on assessment-informed, non-aversive interventions which comprised of skill development and environmental manipulations (Dunlap & Carr, 2007). PBS was later developed as a response to this need.

PBS is a multi-component framework which is used to develop an understanding of the individual’s challenging behaviour. This understanding is then used to develop and implement effective support plans that when appropriately applied, enhance an individual’s quality of life (Dunlap & Carr, 2007; Gore et al., 2013; LaVigna & Willis, 2005). The underlying theory of PBS is based on learning theory and the assumption that all behaviour is learned (NHS Education for Scotland, 2012). This view sees challenging behaviour as an operant behaviour and as such it is determined by positive or negative reinforcement. PBS uses these principles in a person centred and values led approach to altering behaviour (Gore et al., 2013).

The values of PBS are based on human rights movements in the field of ID (Gore et al., 2013). These include preventing and reducing challenging behaviour, increasing quality of life, inclusion, participation and supporting valued social roles for individuals with ID. A key component of PBS is the inclusion of stakeholders, including the individual with challenging behaviour and their family and social networks. This is essential for determining the priorities and targets for support, whilst ensuring plans are suited to the person’s context. An important principle of PBS is that the individual is viewed as more than just their challenging behaviour. The process of PBS should rely on theory and evidence based practice, be data-driven and values-led (Gore et al., 2013). This allows for the most ethical and effective approaches to be utilised based on the data, rather than personal opinion or circumstance. These values are reflected in NICE guidelines for working with people with ID whose behaviour challenges (NICE, 2015).

Gore et al. (2013) suggest that challenging behaviour should be understood as a learnt behaviour which has developed to meet the needs of the individual within the context in which they live, including the physical and social environments. This is in contrast to previous views of challenging behaviour which may have considered it deviant or deliberate. As such, PBS should aim to increase the individual’s repertoire of skills and adaptive behaviour in order to reduce the need for the use of challenging behaviours in the first instance (La Vigna & Willis, 2012). PBS plans are based on functional assessment and include ecological strategies, positive programming designed to teach skills and focused support strategies designed to manage the challenging behaviour and reduce the need for reactive strategies (La Vigna & Willis, 2012). Inclusion of this range of strategies is why the approach is referred to as multi-component and a combination of components is required in order to result in an effective, meaningful and personalised approach (Gore et al., 2013). PBS can be implemented with a single individual or as a system wide approach within residential, educational, family and community settings. Plans should include a definition of the target behaviour and proactive strategies to eliminate antecedents, provide functionally equivalent alternatives to the target behaviour, coping strategies and learning opportunities to reduce the reliance on challenging behaviour in the long term (Gore et al., 2013; La Vigna & Willis, 2012). Monitoring systems should be established to allow for the plan to be reviewed easily and support the data-driven approach.

The majority of strategies included in a PBS plan should be proactive in nature, in order to reduce the occurrence of challenging behaviour in the first instance. Reactive strategies are also included for managing episodes of challenging behaviour when they occur. Physically restrictive strategies can be included in plans but emphasis is put on these being the very last resort due to their restrictive nature. Furthermore, any physical restrictions used should be the least restrictive option and should be documented in a written plan, with a focus on ways to reduce the use of this type of intervention over time. When restrictive strategies are required, PBS focuses on non-escalating approaches and therefore, punishment is not considered appropriate as part of a PBS plan, as it is more likely to escalate behaviours than resolve them and does not fit with the values based principles of the framework (LaVigna & Willis, 2012). PBS is grounded in Applied Behavioural Analysis (ABA) however it places greater importance on ecological and social validity and implementing strategies at all levels of a system (Gore et al., 2013). Furthermore, PBS is open to the use of other, complementary evidence based approaches to support the behaviour change, including psycho-education and therapeutic interventions. Gore et al. (2013) point out that the implementation of PBS plans is a complex process that requires behaviour change from both the individual that displays challenging behaviour and those supporting them and reinforcement of this behaviour change is essential to successful implementation.

### Evidence Base for PBS

Dunlap and Carr (2007) reviewed the literature into PBS and concluded that there is substantial experimental data which supports the use of functional assessment based interventions for reducing challenging behaviour and increasing pro-social behaviour. However, the existing evidence base for PBS spans across many settings and populations. Carr et al. (1999) conducted one of the earliest reviews of the research into PBS and included 109 studies with a total of 230 participants with a range of ages, level of impairment (as a result of ID, ASD and/or pervasive developmental disability) and across a variety of settings, including schools, residential and community settings. Carr et al.’s findings indicated that PBS is a widely applicable intervention which is effective in reducing challenging behaviour in 50-66% of cases, with the most effective interventions being based on functional assessment. Marquis et al. (2000) conducted a meta-analysis on Carr et al.’s data and found that the effect size of the intervention was large and consistent, and concluded that PBS was effective across a range of problems, settings and participant characteristics.

A significant amount of research has been carried out in school settings. Goh and Bambara (2012) conducted a meta-analysis looking at the use of individualised PBS for students with and without disabilities, including ID and ASD. They looked at 83 studies, involving 145 participants overall and found that functional assessment based interventions were effective in reducing challenging behaviour of students and increased their use of appropriate skills. Furthermore, outcomes were found to be maintained for up to two years.

LaVigna and Willis (2012) carried out a review of the literature looking at the use of PBS with severe challenging behaviour across a total of 12 studies and 423 participants of varying ages, diagnoses and levels of functioning. Their qualitatively described results indicate that PBS is effective with severe and high frequency challenging behaviours whilst also being a cost effective intervention.

### Rationale for review

Reviews conducted into the effectiveness of PBS so far have looked at PBS in school settings (Goh & Bambara, 2012), focused on single components of PBS (Dunlap & Carr, 2007) or are now grossly outdated (Carr et al., 1999). La Vigna and Willis’ (2012) review looked specifically at high frequency and severity of challenging behaviour and all reviews included a range of ages, including children, and were across a range of settings.

As far as we are aware, to date there has not been a review looking specifically into the use of the PBS framework solely with adults with ID and challenging behaviour of all frequencies and severities, a population for which PBS is considered best practice. A systematic review of the literature looking into the effectiveness of PBS for adults with ID could give extra weight to this recommendation and provide further insight into the literature, allowing for identification of gaps in the research and suggestions for future direction.

### Objectives

The main objective of this systematic review was to explore the literature around the effectiveness of the PBS framework when used with adults with ID and challenging behaviour. For the purpose of this review, effectiveness was defined as reduction in challenging behaviour, although additional objectives explored other service user outcomes, including quality of life.

The review aimed to address the following questions:

* Is the use of a PBS framework effective in reducing challenging behaviour for adults with intellectual or developmental disabilities, such as ASD?
* Other than impact on challenging behaviour, what other outcomes are experienced by adults with ID when PBS is implemented?
* What is the quality of the evidence base for PBS with adults with ID?
* What gaps exist in the literature and what are the implications of these for future research and clinical practice?

## 

## Method

### Study Eligibility Criteria

#### Population

Participants were adults with intellectual and/or development disabilities, such as ASD, and therefore all participants were 18 years old or older. Criteria for these diagnoses were consistent with the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) such that ID is defined as significantly impaired cognitive and adaptive functioning with onset during childhood (American Psychiatric Association, 2013). ASD is defined as a developmental disorder characterised by social communication and interaction deficits, again with an onset during childhood (American Psychiatric Association, 2013). It was not necessary for the included studies to have described the diagnostic process of the individuals included. As well as having a diagnosis of intellectual or developmental disability, participants must also have demonstrated challenging behaviour as defined by the Royal College of Psychiatrists et al. (2007), as described earlier.

Furthermore, the review was looking at the effectiveness of PBS for adults with ID and was therefore inclusive of the variety of community settings where this population may access, such as residential settings, supported accommodation and employment settings. There are a variety of terms used to describe settings where this population of individuals may live (i.e. residential settings, supported accommodation) but for the purposes of this report, they will be referred to as social care homes and settings throughout

#### Intervention

The interventions included in this review did not have to be specifically called PBS but did need to meet the criteria for a PBS framework. If the intervention was not referred to as PBS then it must have involved an assessment informed, multi-component behaviour plan. Studies which focused solely on impact of PBS training on staff variables were excluded but training studies that involved implementing a PBS plan and measured challenging behaviour as an outcome measure were included. Similarly, studies comparing different forms of PBS, such as Mindfulness Based PBS vs PBS, were included as long as there were pre and post intervention measures.

#### Study selection

This review included experimental studies which investigated the effectiveness of PBS with adults with intellectual or developmental disabilities. Due to a limited number of studies using a RCT or control group design, studies were required to have implemented an intervention and compared baseline and post intervention data as a minimum. This review therefore included single case design studies.

#### Outcomes

The primary outcome this review was interested in was challenging behaviour. This could be measured using formalised measures, such as Aberrant Behaviour Checklist (ABC; Aman, Singh, Stewart, & Field, 1985), or behavioural observations of frequency or severity of target behaviours. Other outcomes were investigated, such as quality of life.

#### Exclusion criteria

Studies were excluded if they included child participants and were not predominately based in community settings. This review is limited to published peer-reviewed studies only. In addition, due to resource constraints, only studies published in English were considered.

No exclusion criteria was applied to the date of publication.

### Search Strategy

Title and abstracts were searched on the PsychInfo and Pubmed databases on 25/11/2018, using the following terms:

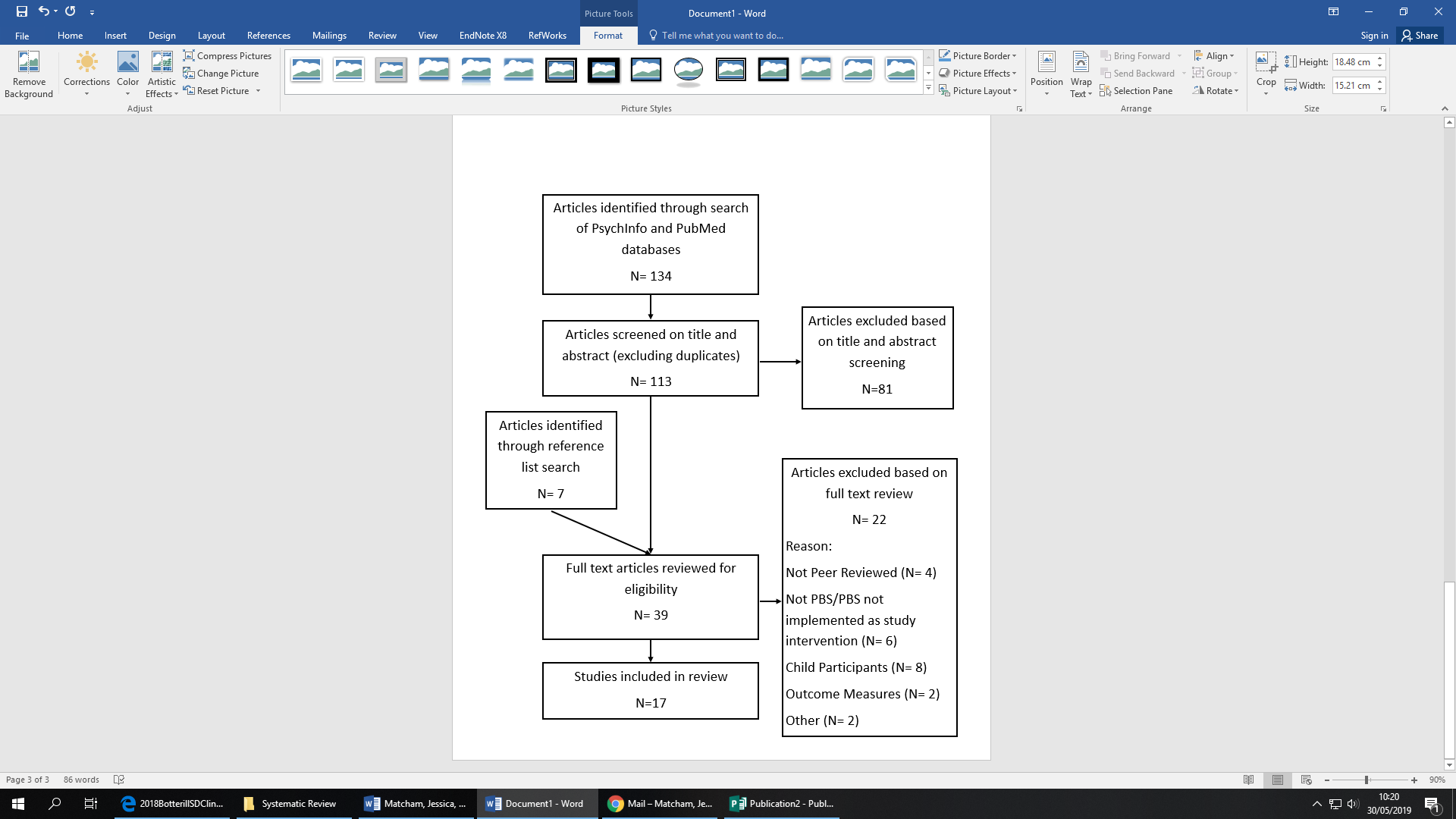
* “Positive behaviour support” OR “positive behavior support” OR “behaviour support” OR “behavior support” OR “behavioural support” OR “behavioral support” OR “behaviour intervention” OR “behavior intervention” OR “behaviour management” OR “behavior management” OR “PBS” OR “behaviour supports” OR “behavior supports” OR “support plan” OR “support plans” OR “behavioural management” OR “behavioral management”
* *AND* “challenging behavior" OR "challenging behaviour" OR "aggression" OR "aggressive behaviour" OR "violent behaviour" OR "aggressive behavior" OR "violent behaviour" OR “violence” OR "self-injury" OR “self-harm” OR “behaviour that challenges” OR “behaviours that challenge” OR "challenging behaviors" OR "challenging behaviours"
* *AND* “Intellectual disability” OR “learning disability” OR “developmental disability” OR “intellectual disabilities” OR “learning disabilities” OR “developmental disabilities” OR “autism” OR “autistic” OR “mental retardation” OR “mental handicap” OR “neurodevelopmental disability” OR “neurodevelopmental disabilities” OR “disability” OR “disabled”
* *NOT* “children” OR “child” OR “teen” OR “teenager” OR “adolescent” OR “teens” OR “teenagers” OR “adolescents” OR “under 18” OR “under eighteen” OR “school” OR “college” OR “educational” OR “childhood” OR “special educational” OR “special education” OR “education” OR “youth” OR “parent” OR “parents” OR “parental” OR “classroom” OR “teacher”

### Study Selection

The search produced 99 articles on PsychInfo and 35 articles on PubMed. The study selection process is shown in Figure 1. Further studies were identified by reviewing the reference lists of studies included from the database search. All 134 studies initially identified were screened by both the researcher and a second reviewer, a psychology Masters student at Royal Holloway, University of London, recruited as a research assistant for this review. This was to ensure that the inclusion criteria were applied consistently. There was a 92% agreement rate between the two reviewers. Discrepancies were discussed and an agreement was reached for 17 articles to be included in this review.

### Data Extraction

Data was extracted from the included studies by the researcher. The research assistant also extracted data from five studies in order to ensure consistency of data extraction across studies. Relevant information extracted included the study design, intervention type, population, sample size, recruitment procedures, attrition rates, blinding, outcome measures, results, confounders, follow up and intervention fidelity.



### *Figure 1. Flow chart of systematic review selection process*

### Assessing Study Methodological Quality

The Quality Assessment Tool for Quantitative Studies (QA Tool; Effective Public Health Practice Project, 1998) was used to rate the methodological quality of the included experimental design studies. Studies rated by this tool are given a rating of either ‘strong’, ‘moderate’ or ‘weak’ across six criteria: selection bias, study design, confounders, blinding, data collection and withdrawals and drop outs. Based on the ratings for each category, an overall rating is also given. This tool was selected as it was developed for use with studies using quantitative data within the public health sector (Thomas, Ciliska, Dobbins, & Micucci, 2004). The tool comes with a dictionary which provides guidance on how to rate each criteria and reduces the influence of individual interpretation and bias (Appendix 1).

This tool as standard is not suitable for single-case designs and appropriate tools for such designs are not available. Therefore, the QA Tool was adapted and a supplement document was created to better suit these studies, based on recommendations from Kazdin (2011). Both the standard tool and supplement document can be found in Appendices 2 and 3 respectively. Specifically, the following areas were adapted:

* *Design*: Single-case studies which utilised an experimental design were considered to have moderate quality. This is based on the existing criteria for the QA Tool which states only RCTs and Controlled Clinical Trials (CCT) are considered strong design methodology.
* *Confounders*: Articles identifying that they considered confounding factors and none were identified were rated as strong. Those that did not consider or identify confounders were rated as weak.
* *Outcome Measures*: Outcome measure ratings completed by the lead researcher or an interventionist that was aware of the research question were scored as weak. This item was scored as moderate if rater was impartial or blind to the research question, or strong where both factors were evident.
* *Maintenance/Follow Up*: A weak score was given if there was no maintenance/follow-up period. Follow ups of more than 2 years were rated as strong and less than 2 years as moderate.
* *Inter-rater Reliability*: Inter-rater reliability was scored as strong where the rater was trained in measuring the outcome and inter-rater reliability was at least 80%. This domain was scored as weak where this was not considered or reported.

Intervention fidelity is a component considered in the QA Tool, however it is not formally rated as standard. Intervention fidelity is a particularly important consideration for the research included in this review, primarily due to the multi-component and individualised nature of PBS frameworks. It is important to consider whether the interventions implemented in the studies are in fact in line with PBS principles and values, and therefore allow for like for like comparisons to be made across the findings of the research. For this reason, the tool was further adapted and the following ratings were applied for this component:

* *Intervention Fidelity:* Where intervention was not measured, not reported or found to be poor, a weak rating was given. Studies that reported intervention fidelity but did not use formal tools to measure this, and those that found moderate adherence to the intervention, were rated as moderate. Studies that formally measured intervention fidelity and found this to be of a high standard were rated as strong.

All studies were rated by the researcher. In order to control for bias, five studies were co-rated by the research assistant. Inter-rater agreement was 80%. Discrepancies in ratings were discussed and an agreement was reached for all studies. Due to the relatively small number of studies identified as eligible for inclusion in this review, no threshold was set for methodological quality and therefore no studies were excluded on this basis.

### Data synthesis

Due to heterogeneity in the type of interventions, study designs and outcome measures used in the included studies, it was not deemed appropriate to complete a meta-analysis. Instead a narrative synthesis of the data will be described.

### Measures of Treatment Effect

Single case design data is often presented graphically and therefore effect sizes are not reported for many of the studies of this nature included in this review. A common outcome metric is necessary for research synthesis (Scruggs & Mastropieri, 1998). If statistical analysis was undertaken and reported, treatment effects are described in terms of statistical significance. Where possible, for studies where statistical significance or effect size are not reported, Points of Non-overlapping Data (PND) was calculated by the researcher and reported in this review.

Developed by Scruggs, Mastropieri, and Casto (1987), PND is a measure of the points in non-baseline phases that do not overlap with the range of points in baseline phases. This metric is an accepted method for synthesizing small-n research (Scruggs & Mastropieri, 2012) and one of the most widely used quantitative methods for evaluating effects in single case research (Vannest & Ninci, 2015). It provides an easy to calculate and meaningful measure of treatment effect, an important criterion for evaluating outcomes (Scruggs & Mastropieri, 1998). For larger data set, i.e. N > 20, Percentage of All Non-overlapping Data (PAND) is considered more appropriate (Lenz, 2013), but as this was not the case for the data included in this review, PND was considered appropriate.

Treatment is considered effective if the PND is calculated to be equal to or greater than 0.7, with results above 0.9 considered very effective (Scruggs & Mastropieri, 1998). Results between 0.5 and 0.7 suggest questionable effectiveness and anything below 0.5 is ineffective.

## Results

In total, 134 studies from the literature search and seven from reference list searches were identified. Once titles and abstracts were screened, 39 full text articles were further screened against the inclusion criteria. From these, 17 met the inclusion criteria and were included in this review. Dates of publication for these studies ranged from 1995-2018. Of those excluded based on screening on full text, eight were due to inclusion of child participants, six due to the interventions implemented, four were not peer reviewed articles and two did not utilise sufficient outcome measures. Two articles were excluded because they were the original study prior to a follow up study or a different version of the same article already included (Hassiotis, Canagasabey, Robotham, Marston, Romeo, & King, 2011; Hassiotis et al., 2018a, respectively). Details of the selection process can be found in Figure 1.

### Study Designs

Table 1 shows a summary of the study characteristics. Of the 17 studies included in the review, 11 employed a single case design. Four studies were RCTs, one of which was a single blind RCT (Hassiotis et al., 2011) and two were cluster RCTs (Hassiotis et al., 2018a; McGill et al., 2018). The review also included one study which utilised a non-randomised control group design (MacDonald, McGill, & Murphy, 2018) and one service evaluation study (Inchley-Mort, Rantell, Wahlich, & Hassiotis, 2014).

All but one single case design utilised an AB design. The remaining study utilised an ABAB approach (Sigafoos & Tucker, 2000). Measurement of a baseline before implementing intervention is good practice for single case designs and improves their methodological quality (Lobo, Moeyaert, Cunha, & Babik, 2017). Although ABAB designs would further enhance their quality, this comes with ethical implications as once effective intervention has been identified, it can be considered unethical to remove this when you expect that the consequence will involve distress of the individual. For PBS research where the capacity of the individual may be limited and the intervention is taking place in their best interest, this is not an ethical procedure to undertake. Furthermore, if an intervention is likely to result in permanent changes, which may occur in PBS due to the skill development aspects, removing the intervention and returning to baseline is not feasible or appropriate (Lobo et al., 2017).

Two of the RCT design studies focused on staff training in PBS (Hassiotis et al., 2018a) and Mindfulness Based PBS (MBPBS; Singh et al., 2018), whilst the remaining two RCT studies investigated the use of PBS vs Treatment As Usual (TAU; Hassiotis et al., 2011; McGill et al., 2018). MacDonald et al. (2018) also investigated the use of PBS vs TAU but used a non-randomised control group design.

The service evaluation measured the outcome of using PBS as a service model within ‘Complex Behaviour Services’ and compared this to matched controls who received usual service procedure provided by multi-disciplinary community teams (Inchley-Mort et al., 2014).

### *Table 1. Summary of Study Characteristics*

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Study** | **Design** | **Participants** | **Intervention Type** | **Outcome Measures** | **Results** | | | **Follow up** |
| Belcher, 1995  *USA* | Single Case Study (AB) | N=1  22 years  Male  Moderate ID  ASD | Multi-component behavioural guidelines | Frequency of target behaviours | Significant decrease in target behaviours (PND=1.00) | | | Maintenance over 3 years |
| Bird & Liuselli, 2000  *USA* | Single Case Study (AB) | N=5 Males  24-34 years  3 Mild ID  2 Moderate ID  3 ASD | Multifaceted Behaviour Support  Removal of restrictive practice | Frequency of target behaviours | Significant decrease in target behaviour for 3 participants (PND=1.00), marginal effect for 1 participant (PND=0.50) and no effect for 1 participant (PND=0.25)  QoL reported to improve anecdotally through greater independence, reduced supervision, and increased diversity in living and work environments. | | | 24 months |
| **Study** | **Design** | **Participants** | **Intervention Type** | **Outcome Measures** | **Results** | | | **Follow up** |
| Bird, Sperry & Carreiro, 1998  *USA* | Single Case Study (AB, Multiple Baselines) | N=10  31-42 years  Mild to “borderline” ID | Multi-component treatment model | Frequency of target behaviours  Quality of Life Questionnaire | Challenging behaviours reduced on an average of 92% (78-100%) from the initial month of placement to the last month of the year.  Of participants able to answer, all reported an increase in degree of satisfaction, perceived productivity, independence and community integration 1 year after entering the program. | | | Follow up at 6 and 12 months |
| Carson, Clare & Murphy, 1998  *UK* | Single Case Study (AB) | N=1  Male  Mid 40s | PBS | Frequency of target behaviour | Significant decrease in frequency of target behaviour during intervention and at follow up (PND=1.00)  Significant increase in engagement in purposeful activity during intervention (PND=1.00) | | | Follow up at 2 weeks and 8 months |
| **Study** | **Design** | **Participants** | **Intervention Type** | **Outcome Measures** | **Results** | | | **Follow up** |
| Hassiotis et al, 2011  *UK* | RCT, Single Blind | N=58 at 2 year follow up  From initial sample (N=63):  37 Males  26 Females  Mean age = 39.6 years  Mild/Moderate ID: 42  Severe/Profound ID: 21 | PBS vs TAU | ABC  PAS-ADD  Treatment Costs | Significantly lower transformed total ABC scores than those in intervention arm compared to TAU (p value not reported).  Differences in the ABC sub-domains irritability, hyperactivity and lethargy were significantly lower in favour of the intervention (p values not reported). | | | 2 years |
| Hassiotis et al, 2018  *UK* | Cluster RCT, Multi Centre, Single Blind, Two Arm | N=246  Intervention Group: 109  Control Group: 137  25-51 years  157 Male  89 Female  50 ASD | PBS training vs TAU | ABC-CT  Secondary:  Mini PASSAD  GCPLA  Uplift/Burden Scale  GHQ-12  CDS-ID  QALYs  CSRI-LD  Medication Use | ABC-CT: Difference between intervention and control not significant (p=0.528).  No treatment effects were found for any of the secondary outcomes. | | | Follow up at 6 and 12 months |
| **Study** | **Design** | **Participants** | **Intervention Type** | **Outcome Measures** | **Results** | | | **Follow up** |
| Inchley-Mort et al., 2014  *UK* | Service Evaluation, Matched Controls | N=46  Intervention Group: 24 Control Group:22  19-86 years  32 Male  14 Female  19 ASD | PBS delivered by “Complex Behaviour Services” | Primary: ABC  Secondary:  1. HoNOS-LD  2. CANDID-s  3. PASSAD | Significant reduction in the following ABC domain scores: Irritability (p=0.03), Stereotypy (p=0.02), Total score (p=0.05)  No significant differences between the CBS and the non-CBS groups at 12 months with respect to secondary outcomes | | | Maintenance over 12 month period |
| Kemp & Carr, 1995  *USA* | Single Case Study (Multiple Baseline) | N=3  26-30 years  2 Males  1 Female  3 ASD | Hypothesis Driven Multi-component Behavioural Intervention | Latency to target behaviour  Social Validity Data | Latency between target behaviour significantly increased for all 3 participants (PND=0.78, 1.00, 1.00) | | | None |
| **Study** | **Design** | **Participants** | **Intervention Type** | **Outcome Measures** | **Results** | | | **Follow up** |
| Luiselli, Sperry & Connolly, 2002  *USA* | Case Study | N= 1  27 years  Female | Community Based, Multi-component Behaviour Support | Frequency of target behaviours  Duration of specific intervention procedures recorded | No baseline data for aggressive behaviour reported. Aggression and self-injury decreased steadily and maintained at manageable levels. Reduced frequencies were maintained long term.  Duration of restraints used significantly decreased (PND=1.00)  QoL improved anecdotally | | | Maintenance over 7 year |
| MacDonald, Hume & McGill, 2010  *UK* | Case Study | N=1  Male | Multi-element behavioural support plan delivered by PBS team | Levels of three types of challenging behaviours  Participation in activity (QoL) | Challenging behaviour significantly reduced across all 3 domains:  Self injury (PND=0.89)  Aggression (PND=1.00)  Destruction (PND=1.00)  Relationship between consistent implementation of the Behaviour Support Plan (as indicated by the PSR scores) and increased participation in activity (Pearson’s r=0.90). | | | 22 month maintenance |
| **Study** | **Design** | **Participants** | **Intervention Type** | **Outcome Measures** | **Results** | | | **Follow up** |
| MacDonald et al., 2018  *UK* | Non Randomised Control Group Design, Within and Between Groups | N=72  Experimental Group: 50  Control Group: 22  18-63 years  48 Male  24 Female  33 ASD | Training in PBS vs TAU | ABC  ASM  ABS  BRF  CHABA  GCPLA (QoL)  MTS  The Knowledge Test  Periodic Service Review  Practice Leadership Questionnaire | ABC: significant reductions were found in frequency (p=0.001) and severity (p=00.01) of target behaviour  MTS : increase in total engagement, although not significant (p=0.129)  GCPLA: No significant change for either range (p=0.735) or busy (p=0.548) scores | | | Follow up at 12 and 18 months |
| McClean, Grey & McCracken, 2007  *Ireland, UK* | Single Case Study (Multiple Baseline) | N=5  21-38 years  3 Male  2 Female  2 ASD | PBS | Frequency of target behaviour  Mini PAS-ADD  QoL Questionnaire  Amount of medication  Periodic Service Review | Frequency of target behaviour significantly decreased for all 5 participants (PND=1.00 for all)  Mini PAS-ADD: symptomatology reduced for 4/5 participants  QoL: Improved for 3 participants, from below the 1st %ile to above the 50th %ile. | | | Follow up at 24 months |
| **Study** | **Design** | **Participants** | **Intervention Type** | **Outcome Measures** | **Results** | | | **Follow up** |
| McGill et al., 2018  *UK* | Cluster RCT | N=81  Intervention group: 38  Control group: 43  19-84 years  35 Males  46 Females | Setting wide PBS | ABC  EMAC-R (QoL)  ASM  Questionnaires completed by family and professionals on their experiences and overall evaluation of the intervention’s impact (social validity) | ABC: Intervention group average score reduced significantly more than control group (p=0.04)  ASM: Intervention group average score increased significantly more than control group (p=0.01)  EMAC-R: No significant difference found in Quality of Life measure between groups but both increased over time  Social Validity: 68% staff reported intervention to have an impact | | | Follow up at 3-6 months and 12-18 months |
| Schall, 2010  *USA* | Case study (AB) | N=1  25 year old  Male  ASD | PBS in Employment Setting | Frequency of target behaviour | Behaviour frequency significantly reduced (PND=1.00) | | | None |
| **Study** | **Design** | **Participants** | **Intervention Type** | **Outcome Measures** | | **Results** | **Follow up** | |
| Sigafoos & Tucker, 2000  *Australia* | Case Study (ABAB) | N=1  19 year old  Male | Multi-component Behaviour Support Plan  FA | ABC | Significant reduction of target behaviour for all 3 intervention components: Noncontingent attention (PND=0.67, 1.00), Opportunity to mand (PND=1.00, 1.00), Leisure Items (PND=1.00, 1.00) | | | None |
| Singh et al., 2018  *USA* | RCT | N=147 care givers  N= 80 service users  24-63 years old  48 Male  32 Female  Mild ID: 55  Moderate ID: 25 | MBPBS Training vs PBS Training | Carer Variables  PSS-10  ProQoL  Training attendance  Meditation practice  Client Variables  Aggressive Events  Staff Injury  Peer Injury  Agency Variables  Physical Restraints  Emergency Medication  One to one Staffing  Staff Turnover  Cost-Effectiveness | All client variables reduced significantly more in the intervention group compared to control (p=0.001).  Similar effects found for physical restraint, emergency medication use and one to one staffing levels (p=0.001). | | | None |
| **Study** | **Design** | **Participants** | **Intervention Type** | **Outcome Measures** | | **Results** | **Follow up** | |
| West & Patton, 2010  *USA* | Single Case Study (Multiple Baselines) | N=4  34-41 years old  2 Male  2 Female | PBS  FA  Supported Employment | Frequency of target behaviours  Response to job tasks | Immediate and complete absence of problem behaviour occurred when involved in community settings and job training  Skills relating to job tasks improved – increase in independence and correct responses | | | None |

*Key: ABC (Aberrant Behaviour Checklist; Aman et al., 1985), ABC-CT (Aberrant Behaviour Checklist – Community total score), ABS (Adaptive Behaviour Scale; Nihira, Leland, & Lambert, 1993), ASD (Autism Spectrum Disorder), ASM (Active Support Measure; Mansell, Elliott, & Beadle- Brown, 2005), BRF (Behaviour Recording Forms; Emerson & Einfield, 2012), CANDID-s (Camberwell Assessment of Needs-Developmental and Intellectual Disabilities-short version; Xenitidis et al., 2000), CDS-ID (Caregiving Difficulty Scale – Intellectual Disability), CHABA (Challenging Behaviour Attribution Scale; Hastings, 1997), CSRI-LD (Client Service Receipt Inventory), EMAC-R (Engagement in Meaningful Activity and Relationships; Mansell & Beadle-Brown, 2005), FA = Functional Analysis, GCPLA (Guernsey Community Participation and Leisure Activities Scale; Baker, 2000), GHQ-12 (General Health Questionnaire – 12 items), HoNOS-LD (Health of the Nation Outcome Survey-LD; Roy et al., 2002), Mindfulness Based Positive Behaviour Support (MBPBS; Singh, Lancioni, Karazsia & Myers, 2016), Mini PASSAD (Mini Psychiatric Assessment Schedules for Adults with Developmental Disabilities), MTS (Momentary Time Sampling; Mansell, Beadle- Brown, Macdonald, & Ashman, 2003), PAS-ADD (Psychiatric Assessment Schedules for Adults with Developmental Disabilities; Moss et al., 1998), Percevied Stress Scale 10 (PSS-10; Cohen, Kamarck & Mermelstein, 1983)Professional Quality of Life (ProQoL; Stamm, 2010), PSR (Periodic Service Review; La Vigna et al., 1994), QALYs (Quality-Adjusted Life-Year), QoL (Quality of Life), QoLQ (Quality of Life Questionnaire; Schalock et al., 1989), TAU = Treatment as Usual*

### Interventions

There were variations in interventions used within the included studies. It is possible to provide details of the individualised and person centred PBS plans in case study designs, where n is small; however this level of detail is not provided for larger studies.

Seven studies did not refer to PBS specifically in the article, but the interventions implemented would all fall within the definition of PBS. This is due to their use of functional analysis or hypothesis driven intervention and the use of multi component plans. Belcher (1995) referred to their intervention as ‘Active Behavioural Treatment’ whilst both Carson, Clare, and Murphy (1998) and MacDonald, Hume, and McGill (2010) referred to the use of multi-component plans based on LaVigna, Willis, and Donnellan’s (1989) framework for positive programming. Two studies investigated PBS in employment settings (Schall, 2010; West & Patton, 2010) and one looked at PBS across both the work and home environment (Bird & Luiselli, 2000).

Three studies looked at the impact of training staff in using PBS. Hassiotis et al. (2018a) provided three two-day face to face workshops focusing on essential components of PBS including functional behavioural assessment, prevention of challenging behaviour, reactive strategies and periodic service review. MacDonald et al. (2018) provided a two day introduction to PBS followed by eight one day workshops over the course of one year, based on LaVigna and Willis’ (2005) framework of PBS. It was practice based and participants were supported to develop and implement function based PBS plans. Both Hassiotis et al. (2018a) and MacDonald et al. (2018) compared their training interventions with treatment as usual. Singh et al. (2018) compared MBPBS and standard PBS. Both groups received a seven day PBS course spread over ten weeks, based on Dunlap, Heineman, Knoster, Fox, Anderson, and Albin’s (2000) PBS framework, however the MBPBS group were also provided with informal meditation practices that could be used in specific work situations.

Inchley-Mort et al. (2014) conducted a service evaluation which looked at PBS delivered by ‘Complex Behaviour Services’, whilst McGill et al. (2018) implemented setting wide PBS in supported accommodation services. Neither study reported specific details about the interventions delivered to service users.

### Participants

Overall, 621 participants were included in the review with ages ranging from 18-86 years. Where reported, the majority of participants were male (N=374), with 237 females being included. Bird, Sperry, and Carreiro (1998) did not specify the genders of the ten participants included in their single case series design study. There was a relatively equal split across the UK and USA, with eight studies being conducted in the USA and seven in UK. The remaining two studies were single case studies conducted in Australia (Sigafoos & Tucker, 2000) and Ireland (McClean, Grey, & McCracken, 2007). There was a large variation in range of severity of ID, with some studies not reporting specific levels (Carson et al., 1998; Hassiotis et al., 2018a; Kemp & Carr, 1995; MacDonald et al., 2010; MacDonald et al., 2018; McGill et al., 2018; Sigafoos & Tucker, 2000; Singh et al., 2018) and others including participants with “any severity” (Hassiotis et al., 2011). Only one participant in a single case study was not reported to have an intellectual disability but had a diagnosis of ASD (Schall, 2010). In total, 62 participants had a diagnosis of ASD. All participants were described as displaying challenging behaviours. Other diagnoses documented included epilepsy, cerebral palsy, mental health problems and sensory impairments.

Six studies did not report information relating to recruitment of participants, all of which were single case series design (Belcher, 1995; Bird & Luiselli, 2000; Luiselli, Sperry, & Carriero, 2002; MacDonald et al., 2010; Schall, 2010; Sigafoos & Tucker, 2000). The majority of studies recruited participants from local services. MacDonald et al. (2018) recruited staff participants for training based on employees who were already enrolled in an upcoming training course, whilst McClean et al. (2007) recruited the five people with the most challenging behaviour in Ireland, based on the Harris Challenging Behaviour Checklist (Harris, 1993).

Attrition rates were not reported in any single case study designs but no participants dropped out or were removed from the studies. One of the six experimental design studies did not report attrition rates (Inchley-Mort et al., 2014), however the data suggests there were 20% fewer participants at the end of the study. Three studies report attrition rates were lower than 10% (Hassiotis et al., 2011; MacDonald et al., 2018; Singh et al., 2018). Hassiotis et al. (2018a) report a 25% drop out rate whilst McGill et al. (2018) report rates between 44-61% at follow up.

### Outcome Measures

All studies included a measure of challenging behaviour. Ten studies measured the frequency of the target behaviour, whilst six studies used the Aberrant Behaviour Checklist (ABC; Aman et al., 1985) as the primary outcome measure. Kemp & Carr (1995) measured the latency of target behaviour and two studies also measured the duration of target behaviours (Luiselli et al., 2002; MacDonald et al., 2010).

Behavioural observation is appropriate for single case and evaluating PBS when the main goal is to reduce target behaviour. Assessment of inter-rater reliability is often essential for research designs that collect observational ratings (Hallgren, 2012). Six studies reported inter-rater reliability which ranged from 87-100% (Bird & Luiselli, 2000; Bird et al., 1998; Carson et al., 1998; Kemp & Carr, 1995; McClean et al., 2007; Sigafoos & Tucker, 2000). Although doing so did add to the methodological quality of the studies, all six studies reported a percentage rating. This is not considered an adequate measure of inter-rater reliability unless ratings have been corrected for agreements that would be expected by chance (Hallgren, 2012) and consideration of this was not reported in any studies.

MacDonald et al. (2018) checked inter rater reliability on their measure of quality of life, Momentary Time Sampling (MTS; Mansell, Beadle- Brown, Macdonald, & Ashman, 2003) to measure quality of staff support and service user engagement. MTS was checked for reliability using a second blind reviewer but noticeable differences were found and a proportion of the data was re-coded as a result. Luiselli et al. (2002) did not provide inter rater reliability ratings but did report having trained the staff in the recording protocol, which is likely to benefit the reliability of the ratings.

PBS focuses on behavioural change but also emphasises the importance of developing adaptive behaviour and improving quality of life (Gore et al., 2013; La Vigna & Willis, 2012). These are areas which are not focused on as much in research previously (Carr et al., 1999). In this review, eight studies included measures of either quality of life, adaptive behaviour or both (Bird et al., 1998; Carson et al., 1998; Hassiotis et al., 2018a; MacDonald et al., 2010; MacDonald et al., 2018; McClean et al., 2007; McGill et al., 2018; West & Patton, 2010). Measures used included the MTS as previously mentioned, Quality of Life Questionnaire (QoLQ; Schalock, Keith, Hoffman, & Karan, 1989), Guernsey Community Participant and Leisure Assessment (GCPLA; Baker, 2000) or Engagement in Meaningful Activity and Relationships observational measure (EMAC-R; Mansell & Beadle-Brown, 2005)

In order to ensure validity of observational data, it is recommended that social validity checks are conducted (Kazdin, 2011). Only one study reported data relating to social validity (McGill et al., 2018). Other service user outcome measures included the HONOS-LD (Inchley-Mort et al., 2014), PASADD/Mini PASADD (Hassiotis et al., 2011; Hassiotis et al., 2018a; Inchley-Mort et al., 2014; McClean et al., 2007) and medication use (Hassiotis et al., 2011, McClean et al., 2007; Singh et al., 2018).

### Outcomes

#### Behavioural Outcomes

Of the 17 studies included in this review, 13 reported statistically significant results in favour of PBS being effective for at least one measure of target behaviour. These results were either directly reported as a P value or calculated by the researcher as a PND. Three single case series design studies do not provide sufficient data to calculate the PND, although all report a reduction in challenging behaviour (Bird et al., 1998; Luiselli et al., 2002; West & Patton, 2010). In contrast, Hassiotis et al. (2018a) found no significant difference between the intervention and control group for behavioural outcomes and the authors concluded that staff training in PBS did not reduce levels of challenging behaviour. An overview of results can be found in Table 1.

Despite the majority of studies showing some degree of effectiveness, some studies demonstrated mixed results. Both Bird and Luiselli (2000) and Sigafoos and Tucker (2000) reported a range of effectiveness across the participants, with the lowest values being 0.25 and 0.67 respectively, both of which are lower than the 0.70 PND required to be considered effective (Scruggs & Mastropieri, 1998). However both studies report a general reduction in the target behaviour, despite this not being significantly different for a proportion of their participants.

Mixed results were also found on the ABC, a measure of challenging behaviour. Hassiotis et al. (2011) reported significant reduction in the lethargy and hyperactivity domains of this measure, whilst MacDonald et al. (2018) reported significant reduction in frequency and severity of challenging behaviour. Inchley et al.’s (2014) service evaluation reported a significant reduction for two of the domains measured on the ABC, stereotypy and irritability, post intervention. It is worth noting that in the text body of their report it states the reduction in stereotypy remains significant at 12 month follow up, however this is not reflected in the table statistics (p=0.63 adjusted) so it is unclear whether the effect on stereotypy was continued at follow up or not.

#### Quality of Life

Four studies utilised a formal measure of quality of life and the results are varied. Hassiotis et al. (2018a) found no treatment effects for their secondary outcome measures, including the GCPLA, which measures quality of life. McGill et al. (2018) found no significant change on their quality of life measure, EMAC-R. MacDonald et al. (2018) reported an increase, albeit non-significant, in the MTS scale, and no significant change in either the range or busy domains of the GCPLA. McClean et al. (2007) reported an improvement in quality of life for three out of five participants, with their scores increasing from the 1st percentile to the 50th on the QoLQ.

Carson et al. (1998) did not use a formal measure of quality of life but recorded frequency data of participant’s engagement with purposeful activities, a component of quality of life (Levasseur, Desrosiers, & Noreau, 2004; Northway & Jenkins, 2003), and found a significant increase post intervention. Similarly, although not measured formally, two studies anecdotally report improvements to quality of life (Bird & Luiselli, 2000; Luiselli et al., 2002). These improvements include greater independence, reduction in supervision and an increase in the diversity of environments accessed and inclusion in the community. The studies looking at PBS in employment settings reported increased time in employment (Kemp & Carr, 1995) and improvement to job related skills and independence (West & Patton, 2010).

#### Social Validity

As previously mentioned McGill et al. (2018) were the only authors to utilise a measure of social validity in the form of a questionnaire looking into the experiences of staff and family members involved in implementing intervention. They reported that 68% of staff and family members in the intervention arm of their RCT reported the intervention to have had a positive impact.

#### Follow Up and Maintenance

A previously reported limitation of PBS research is the lack of adequate follow ups post intervention (Carr et al., 1999). This is an area of the research which appears to have improved with time, with seven of the included studies having a follow up or maintenance period greater than 18 months (Belcher, 1995; Bird & Luiselli, 2000; Hassiotis et al., 2011; Luisell; MacDonald et al., 2010; McClean et al., 2007; McGill et al., 2018), with one study using data recorded over a period of seven years (Luiselli et al., 2002). Six studies had a follow up or maintenance period between four to twelve months (Bird et al., 1998; Carson et al., 1998; Hassiotis et al., 2018a; Inchley-Mort et al., 2014; MacDonald et al., 2018; Schall, 2010). The remaining four studies included no follow up or maintenance period.

### Quality of Studies

Using the adapted QA tool and supplement designed for case studies, none of the 17 studies were rated as having strong overall methodological quality. Six studies were considered moderate (Bird et al., 1998; Hassiotis et al., 2011; Hassiotis et al., 2018a; MacDonald et al., 2018; McClean et al., 2007; Singh et al., 2018) with the remaining 11 studies being considered weak. Details of methodological quality ratings can be found in Tables 2 and 3, with Table 2 representing RCT/experimental designs and Table 3 representing single case study designs.

### *Table 2. Methodological Quality Assessment Ratings for Experimental Design Studies*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | ***Hassiotis et al., 2018*** | ***Hassiotis et al., 2011*** | ***Inchley-Mort et al., 2014*** | ***MacDonald et al., 2018*** | ***McGill et al., 2018*** | ***Singh et al., 2018*** |
| **Selection Bias** | Moderate | Moderate | Moderate | Moderate | Moderate | Moderate |
| **Design** | Strong | Strong | Moderate | Moderate | Strong | Strong |
| **Confounders** | Moderate | Strong | Moderate | Strong | Strong | Weak |
| **Blinding** | Moderate | Strong | Weak | Weak | Weak | Strong |
| **Data Collection** | Strong | Strong | Strong | Strong | Strong | Strong |
| **Drop Outs** | Strong | Strong | Moderate | Moderate | Weak | Strong |
| **Intervention Fidelity** | Weak | Weak | Weak | Moderate | Moderate | Moderate |
| ***Overall*** | ***Moderate*** | ***Moderate*** | ***Weak*** | ***Moderate*** | ***Weak*** | ***Moderate*** |

### *Table 3. Methodological Quality Assessment Ratings for Single Case Study Designs*

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | ***Belcher, 1995*** | ***Bird & Luiselli, 2000*** | ***Bird et al., 1998*** | ***Carson et al., 1998*** | ***Kemp & Carr, 1995*** | ***Luiselli et al., 2002*** | **MacDonald et al., 2010** | **McClean,**  **Grey &**  **McCracken, 2007** | **Schall, 2010** | **Sigafoos & Tucker, 2000** | **West & Patton, 2010** |
| **Selection Bias** | Moderate | Moderate | Moderate | Moderate | Moderate | Moderate | Moderate | Moderate | Weak | Moderate | Moderate |
| **Design** | Moderate | Moderate | Moderate | Moderate | Moderate | Weak | Moderate | Moderate | Moderate | Moderate | Moderate |
| **Confounders** | Weak | Weak | Weak | Weak | Weak | Weak | Weak | Weak | Weak | Weak | Weak |
| **Blinding** | Moderate | Moderate | Moderate | Moderate | Weak | Moderate | Moderate | Moderate | Moderate | Moderate | Moderate |
| **Follow up/ Maintenance** | Weak | Strong | Moderate | Weak | Weak | Strong | Moderate | Moderate | Weak | Weak | Moderate |
| **Outcome Measure Reliability** | Weak | Moderate | Moderate | Moderate | Moderate | Moderate | Weak | Moderate | Weak | Moderate | Weak |
| **Intervention Fidelity** | Weak | Weak | Moderate | Moderate | Weak | Weak | Weak | Moderate | Weak | Weak | Weak |
| ***Overall*** | **Weak** | **Weak** | **Moderate** | **Weak** | **Weak** | **Weak** | **Weak** | **Moderate** | **Weak** | **Weak** | **Weak** |

Of the 11 studies considered weak, nine of these were single case study designs. Only two single case designs scored as moderate (Bird et al., 1998; McClean et al., 2007). The quality of both studies was reduced due to their lack of consideration and control of confounding variables. This was an issue with the single case series studies across the board, with all 11 studies scoring as weak in this domain.

Nearly all single case designs were considered moderate in Selection Bias, Design and Blinding, with only one study being rated as weak for each (Schall, 2010; Luiselli, et al., 2002; Kemp & Carr, 1995, respectively). The single case study designs were considered moderate due to their experimental nature and utilising an AB or ABAB approach, a design which allows for thorough investigation of intervention effects (Lobo et al., 2017). Blinding was rated as moderate if the rater was either impartial to the search or blind to the research question. For the single case series designs included in this review, the majority of them scored as moderate in this domain due to the rater being impartial to the research, for example when observational data was not recorded by a researcher of the study. Selection bias is considered moderate when participants are recruited from a clinic which is likely to represent the general population of participants, which was the case for the majority of the single case series studies and all experimental designs.

For the experimental design studies, the strongest domain was data collection with all six studies scoring highly as the measures used were known to be reliable and valid. The quality of McGill et al.’s (2018) RCT study, which was rated as weak overall, was hindered by their lack of blinding and high dropout rates. Inchley-Mort et al.’s (2014) overall rating was weakened by a lack of blinding and measurement of intervention fidelity. Blinding and intervention fidelity domains were the weakest amongst the six experiment design studies, with three studies rating weak for blinding (Inchley-Mort et al., 2014; MacDonald et al., 2018) and three studies rating weak for intervention fidelity (Hassiotis et al., 2011; Hassiotis et al., 2018a; Inchley-Mort et al., 2014).

As previously mentioned, intervention fidelity is considered particularly important and relevant for this review due to the individualised and variable nature of the PBS framework. Nine studies did not measure or report information relating to intervention fidelity (Belcher, 1995; Bird & Luiselli, 2000; Hassiotis et al., 2011; Inchley-Mort et al., 2014; Kemp & Carr, 1995; Luiselli et al., 2002; Schall, 2010; Sigafoos & Tucker, 2000; West & Patton, 2010). Of those measuring intervention fidelity, three studies utilised a Periodic Service Review (PSR; MacDonald et al., 2010; MacDonald et al., 2018; McClean et al., 2007). PSR is a self-report measure which enables staff to assess the quality and consistency of PBS provided to service users (Lowe et al., 2010). MacDonald et al. (2018) reported a measurement of implementation as 66%, which is below the standard of 85% considered most likely to indicate consistent implementation (La Vigna et al., 1994). Out of the five participants included in McClean et al. (2007), only two participants’ plans were implemented above the level recommended by La Vigna et al. (1994), whilst the remaining three were reported as 80%, 74% and 48%. It is worth noting that the reported levels were the maximum implementation rates recorded over the 24 month of intervention implementation. MacDonald et al. (2018) report finding a strong link between consistent implementation of the behaviour support plans implemented, as indicated by the PSR scores, and increased participation in activities (Pearson’s r=0.90) but did not describe the rates of procedural integrity.

Hassiotis et al. (2018a) used the Behaviour Intervention Plan Quality Evaluation Scoring Guide II (BIP-QE II) to independently assess the quality of behaviour plans. The BIP-QE II is a quality assessment measure which assesses the extent to which 12 important domains of behaviour plans are present in an individual’s plan and is reported to have good reliability and validity (Hassiotis et al., 2018b). From the total of 61 data sets assessed, only 33 contained enough information to be scored and all were deemed to be ‘weak’ quality plans. The remaining 28 plans did not have sufficient information to assess the procedural integrity. This poor intervention fidelity was attributed to reluctant participants, who were not best placed, resourced or supported to implement the behaviour support plans. It has also been suggested that the training itself was not fully implemented in the first instance, as very few participants completed the required work in between sessions (MacDonald, 2018). These issues raise the question of whether it was in fact PBS that was implemented in this study at all.

Carson et al. (1998) reported anecdotal information regarding fidelity to intervention, stating that only the ecological manipulations were fully implemented, whereas positive programming and reactive strategies were only partially implemented. They explained these difficulties as a result of low morale and staff changes. Two studies reported that staff teams conducted reviews of implementation. Bird et al. (1998) conducted bi-weekly reviews and reported they modified procedures to ensure interventions were implemented correctly. McGill et al. (2018) conducted monthly reviews and reported that despite variance in implementation an average of 80% of the standards set were achieved. Using independent trainers, Singh et al. (2018) measured the fidelity to the training for both the control and treatment groups and found this to be 100% for both.

## Discussion

This review set out to explore whether PBS is effective in reducing challenging behaviour for adults with intellectual or developmental disabilities, what other outcomes are experienced by service users when PBS is implemented, what the quality of the evidence is for PBS with this population, what gaps exist in the literature and the implications of these for future research and clinical practice. The following discussion demonstrates how these aims have been achieved and provides an evaluation of the current review.

### Summary of Outcome Findings Relating to Challenging Behaviour

As far as we are aware, this is the first review to look into the effectiveness of PBS in the ID population with adults only. In total, four of the studies included were RCTs, one study was a non-randomised control trial, one was a service evaluation and the remaining 11 were single case study designs. Overall, it appears that PBS is an effective intervention for reducing challenging behaviour. Of the fourteen studies where statistical analysis was calculated, only one study failed to find a significant difference pre and post intervention. Hassiotis et al. (2018a) reported no significant difference between the intervention and control group in their RCT, which aimed to evaluate the impact of trained staff implementing PBS primarily on challenging behaviour, although secondary outcomes were also measured. However, the plans implemented as part of this study were evaluated using a reliable and valid measure (BIP QE II; Hassiotis et al., 2018b) which found them to be either ‘weak’ or to not have sufficient data to assess. This suggests that it was not PBS itself that was ineffective, but the intervention plans specifically implemented in this study were not effective, the majority of which did not meet the criteria to be regarded as PBS (MacDonald, 2018). Given this poor intervention fidelity, it is reasonable to suggest that no meaningful conclusions in regards to PBS’s impact on challenging behaviour can be gathered from this study.

Some of the effective results are limited to a particular type of behaviour. The behaviours that are thought to be affected by the intervention varied across studies which utilised the ABC as an outcome measure (Hassiotis et al., 2011; Inchley-Mort et al., 2014; MacDonald et al., 2018). This may be a reflection of the different behaviours that the individualised interventions were targeting, although further investigation into this would provide clarity on the impact of PBS. One measure of social validity found that 68% of stakeholders thought PBS has a positive impact on the service users it was implemented with (McGill et al., 2018).

### Other Outcomes of PBS

As well as behavioural outcomes, service user outcomes such as quality of life were also reviewed. The majority of studies did not evaluate the impact of PBS on quality of life. Of the four studies that used formal measures of quality of life (Hassiotis et al., 2018a; McGill et al., 2018; MacDonald et al., 2018; McClean et al., 2007), only McClean et al. (2007) found a statistically significant improvement in this domain post intervention. Interestingly, three of the four studies that utilised a formal measure of quality of life were published within the last year, which suggests a recent and welcomed shift towards evaluating this concept within this field.

Participation in meaningful and enjoyable activities is considered a component of quality of life (Levasseur et al., 2004; Northway & Jenkins, 2003) and this was found to improve post intervention in four studies. Carson et al. (1998) found a significant increase in engagement in purposeful activity, whilst McGill et al. (2018), MacDonald et al., (2018) and MacDonald et al. (2010) report a non-significant increase in this domain. MacDonald et al. (2018) used the MTS as an observant measure for evaluating engagement in purposeful activities. They suggest the lack of significant treatment effect may be attributed to the already high level of engagement already noted at baseline. Furthermore, both studies that implemented PBS in the employment settings reported greater independence and participation in the workplace (Schall, 2010; West & Patton, 2010). Although participation increased in these studies, it may be considered reductionist to view this as an improvement in quality of life overall, as this is considered to fall under just one out of four domains of quality of life described by Fallowfield (1990): Psychological, Social, Occupational and Physical.

Quality of life is considered a complex and difficult concept to measure (North & Jenkins, 2003; Testa & Simonson, 1996). Both the GCLPA and QoLQ tools used within the included studies are specifically designed for use within ID populations, however they showed different results, with Hassiotis et al. (2018a) finding no significant increase in quality of life using the GCLPA and McClean et al. (2007) finding a significant improvement on the QoLQ. Both of these measures are informant reports and this may have impacted on the results of the measures. Furthermore, given the damning results of Hassiotis et al.’s (2018a) intervention fidelity as previously mentioned, it is reasonable to suggest that the lack of treatment effect for quality of life is a direct result of poorly implemented interventions, rather than a true representation of the impact of PBS on individuals’ quality of life. Other studies did not measure intervention fidelity and therefore it is not possible to comment on whether this may have impacted on their quality of life measures, but intervention fidelity may be a factor in the mixed results demonstrated in this area.

None of the studies included service users directly in the measurement of their quality of life. Due to cognitive and communication difficulties, individuals with ID are likely to require an adapted quality of life measure in order to fully capture the complexities of their lives (Northway & Jenkins, 2003). There is recognition of a lack of accessible, self-report quality of life measures for individuals with ID (Raczka, Theodore, & Williams, 2018), which is likely to account for the lack of use of appropriate measures within the studies included in this review. Alongside the shift towards measurement of quality of life in PBS research, there is a growing need for development of appropriate measures for this population. Raczka et al. (2018) have worked towards developing such measures with an initial validation of the Mini-MANS-LD, an adapted version of the MANS-LD (Maslow Assessment of Needs Scale Learning Disabilities; Skirrow & Perry, 2009). They found acceptable psychometric properties for this measure and suggest it has the potential to support individuals with ID to subjectively report on their quality of life.

### Methodological Quality of Studies

Overall, 11 of the included studies were considered weak in terms of their methodological quality and none were rated as strong overall. The remaining six were rated as moderate. Of the 11 weak studies, nine of these were single case designs, despite the supplement tool being developed to consider the specific qualities of single case study designs. One of the difficulties of studying PBS is that the interventions by nature are person centred and individualised, and hence lend themselves well to single case series designs. Despite their limitations, there are benefits of using single case series designs and when designed rigorously they can allow for assessment of causal relationships amongst interventions and outcomes (Lobo et al., 2017). Furthermore, results can be generalised when replication of findings are shown across a range of participants, setting and contexts. In addition, single case designs can be considered of equal quality to RCTs (Logan, Hickman, Harris, & Heriza, 2008) and it may be that in this review the measure of quality assessment was not reflective enough of their strengths. Further discussion of this point is provided later.

The variation in intervention can make it difficult to conduct large scale RCTs, which are considered the highest standard of research available. Allen, Jones, and Nethell (2018) highlight a clash between the demands of a RCT study and studying real-life, complex psychosocial interventions such as PBS, which they suggest is reflected in the outcomes of Hassiotis et al.’s (2018a) RCT study. Despite using this gold standard design, all four RCT studies included in this review were only considered moderate in their overall rating. Of these studies, one was let down by a lack of blinding (MacDonald et al., 2018) and another due to lack of consideration of confounding variables (Singh et al., 2018). Hassiotis et al. (2011) and Hassiotis et al (2018a) both scored poorly on the intervention fidelity measured which lowered their overall rating, however this was for different reasons. Hassiotis et al. (2011) did not provide any measure of intervention fidelity; hence a weak rating was applied for this domain. On the other hand, as previously mentioned, Hassiotis et al.’s (2018a) measure of intervention fidelity was found to be poor. As the measure used (BIP QE II) was considered to be reliable and valid (Hassiotis et al., 2018b), the findings in regards to intervention fidelity raise the question as to whether this study should be included in the literature looking into the impact of PBS in this population, when the intervention actually implemented does not meet the criteria to be considered PBS in the first place.

Two studies looked into expanding PBS beyond the individual and conducted an evaluation study (Inchley-Morty et al., 2014) or implemented system wide PBS (McGill et al., 2018). Although these studies were both rated as weak, it may be that the quality assessment measure used did not capture the social validity of these studies, which may have boosted their overall rating if it did. Neither study included blinding as an element of the design, which is not always possible when implementing an intervention as those implementing it have to be aware of what they are doing. Furthermore, McGill et al.’s (2018) rating was weakened by high dropout rates, as previously described.

### Strengths and Limitations of the Literature

Despite the challenges with implementing PBS in large scale studies, six of the included studies did so. Most of these studies were very recent, with four of them being conducted in 2018. Furthermore, more studies seem to be including measures of quality of life and adaptive behaviours, which is in line with the values of PBS and reflects that it is a framework with a holistic view of the individual that attempts to do more than simply reduce challenging behaviour. Follow up and maintenance periods were generally good, another improvement on previous research conducted in this area (Carr et al., 1999). The included studies also tended to have reasonable retention rates. Many studies did not describe details of how participants were recruited, particularly the single case designs. It may be that the participants with ID were recruited in their best interest due to a lack of capacity to provide fully informed consent, as was the case for the participant in Carson et al.’s (1998) single case study. Therefore, it may be that retention rates were generally good because participants were unaware of their involvement in the studies and therefore could not withdraw. This differed to McGill et al.’s (2018) study which had high levels of drop out. This study included clusters of services which also had high dropout rates (48% at follow up for the intervention group and 23% for the control group). As the services dropped out, it is likely that participants were no longer able to be involved in the study, and hence their retention rate dropped also. Reasons for service drop out were reported and included staff withdrawing consent, service closure and setting not providing sufficient data.

In the spirit of extending the outcomes of PBS beyond challenging behaviour, many studies also included measures of staff outcomes. For example, Singh et al. (2018) measured staff variables such as perceived stress levels and professional quality of life. As these are the individuals who are implementing the intervention in the everyday environment, it seems reasonable to suggest that this benefits the PBS literature. Stakeholder involvement is a key principle of PBS and therefore including them in the outcomes is in line with the values of PBS. The majority of studies used frequency of target behaviour as the primary outcome measure and a strength of many studies was the use of inter rater reliability ratings, which tended to be high.

A number of limitations also exist in regards to the literature. Many studies did not report consideration of confounding variables. It is possible that other factors were at play when PBS was implemented as the individuals with ID lives can be complex and multi-faceted. This limitation of the research is reflective of the limited view that is often held about the impact of stressors and changes on individuals with ID’s lives. In addition, measurement of social validity is considered important in clinical treatment research (Foster & Mash, 1999). This is not reflected in the PBS research, with only one of the 17 studies including this as a measure.

As previously mentioned intervention fidelity is considered particularly important when considering the multi-component and individualised nature of PBS frameworks. Ten of the 17 studies included in this review did not consider or report measurement of intervention fidelity. Of those that did, none were rated as strong in this domain. One of the biggest challenges with synthesising the data related to PBS is related to the intervention itself. As by nature there is going to be variance amongst the plans, it is difficult to determine what exactly is being implemented and measured. For this reason, measures of intervention fidelity are crucial for high quality research in this area and the lack of such measures is a significant weakness in the literature currently available.

Although visual analysis of single case design studies is the most widely used form of analysis, it is recommended that it is supplemented with effect size data in order to provide standardised results (Vannest & Ninci, 2015). None of the single case studies included in this review reported effect sizes. Although it was possible to calculate the PND for most of these studies, it is not possible to calculate confidence intervals for this value, an index of reliability which should always be provided with statistical data (Parker & Brossart, 2003).

### Strengths and Limitations of the Review

This review is one of the first to look into the use of the PBS framework with adults with ID in social care settings and provides a valuable contribution to this research area. The review process was strengthened by the extensive use of reliability checks throughout. A second reviewer conducted checks around all areas where decision making and researcher judgement was required, including study inclusion, rating methodological quality and data extraction. The use of a second reviewer in this way increased the reliability of findings. In addition, the search terms used within this review were able to capture a sufficient representation of the research. Both titles and abstracts were searched which would have increased the inclusivity of the search results. However, although the databases used were appropriate for the research question being address, it may be that journals not indexed on these databases were not included in the review. This could explain why a considerable proportion of the included studies were identified through reference list searches, rather than from the initial database search. This reflects a limitation of the review as it suggests that other relevant evidence from journals not indexed on the searched databases may have been missed.

A further limitation to this review is that all studies were conducted in high income, western societies, mainly the UK and USA, and therefore it is not possible to generalise the findings from this review beyond these cultures. This limitation was further hindered by the inclusion criteria of English language studies only, however due to limited resources available to the researcher inclusion of non-English language studies was not possible. In addition, a decision was made to only include published, peer-reviewed articles in this review. This increases the risk of publication bias as articles which are published are more likely to show significant results (Egger & Smith, 1998).

The only inclusion criteria for participants in this review were being over the age of 18 and having a diagnosis of an ID or developmental disability, such as ASD. This means that there was no consideration of the physical or mental health of the participants included in this review. It is well established that individuals with ID and ASD have a higher risk of experiencing co-morbidities (Gillberg & Soderstorm, 2003), however the review is not able to conclude how the effectiveness of PBS may vary amongst different subgroups.

All included studies were assessed for methodological quality, which allows for consideration of the meaningfulness and reliability of the findings presented. This seems particularly important given the lack of well controlled, high quality studies conducted in this area. A strength of the quality assessment methods used in this review is the adaptation to the tools used to include assessment of intervention fidelity, an important and relevant domain to this research area.

For this review the QA Tool was used to assess experimental studies. This tool has been assessed for reliability and validity, and is considered a standardised tool for these types of study designs (Thomas et al., 2004). It was therefore deemed to be the most appropriate tool to use for experimental studies. Although specific assessment tools exist which can be used to assess methodological quality of single case design studies, (Single-Case Reporting Guideline in Behavioural Interventions, SCRIBE; Tate, et al., 2016), it was decided that in order to promote comparability between these two types of study designs, the QA tool would be adapted to suit components of single case designs. This allowed for some continuity of measurement amongst the two groups of research and applied rating systems. However, by measuring methodological quality in this way, it reduces the validity of the measure for single case designs as it is not specifically designed for use with these types of studies. A further limitation is that by restricting the criteria for single case designs to weak or moderate only, the strengths of these design types in this domain were not recognised in this review.

The quality of single case studies is likely to have been more accurately represented by using an assessment tool specifically designed for single case studies, such as SCRIBE (Tate et al., 2016). However, when considering the other limitations of the included studies not pertaining to study design, no study would have been upgraded to strong overall, should the criteria for study design been more lenient. This would have required the studies to have no weak ratings for any other category being assessed, which was not the case for the included studies. Although in hindsight a different approach may have been more reflective of the strengths of single case design studies, it would still leave us with significant limitations more broadly regarding this area of research, as previously discussed in the prior section of this report.

Finally, PND was calculated as it was deemed appropriate for small n studies and is a commonly used analysis in single case study data. Although it has received criticism for not accurately representing the richness of a single case design, Scruggs and Mastropieri (1998) argue that it does provide an objective, systematic and replicable interpretation of the data. As a potential improvement to the design of this review, a qualitative component could have been included in order to ensure that the richness of single case design studies was considered within the evidence identified.

### Implications for Research and Clinical Practice

This review has important implications for clinical practice. The findings show that PBS is an effective intervention for challenging behaviour displayed by adults with ID or developmental disabilities. It is in line with the best practice recommendations that PBS should be used with this population (British Psychological Society & Royal College of Psychiatrists, 2016; NHS England, 2017; NICE, 2015) and this should be continued and encouraged where appropriate. This review identified that intervention fidelity was moderate at best and further exploration of reasons for this in practice are needed. This finding is in line with previous research that suggests implementation of high quality PBS in practice is limited, despite the evidence base and best practice guidance supporting its use with this population (Emerson et al. 2000; MacDonald & McGill, 2013). Further understanding of what supports and hinders implementation with adults with ID would benefit the application of this approach in practice.

This review also has implications for research in this field and suggests more well-controlled, larger scale studies are required in this area. Further development of reliable and valid self-report measures of quality of life for individuals with ID would allow for understanding of the impact of PBS on this domain to be developed. Future research may benefit from identifying specific components of PBS that are likely to be most effective and for which behaviour subtypes. This would allow for specific interventions to be individualised in a way that is going to be most effective to those involved. It was noticeable throughout the included research that outcome measures tended to be observational or stakeholder accounts. It may benefit the literature to explore more service user reports of outcomes. This may lend itself well to demonstrating the impact of PBS on quality of life, as self-report measures may be more appropriate for capturing data relating to this concept. Furthermore, greater measurement of social validity would allow for a better understanding of the impact of the approach in real world settings.

### Conclusion

In conclusion, despite the substandard quality of research, the general consensus from the studies reviewed is that PBS has a positive impact on this population and is effective at reducing challenging behaviour for adults with ID or developmental disabilities. Furthermore, the values of PBS are in line with the wider values of health care services at present, including person centred, individualised care, increased patient choice, improving lives and inclusion (Health Education England, 2017). Therefore, results from this review suggest that PBS should continue to be recommended as best practice (British Psychological Society & Royal College of Psychiatrists, 2016; NICE, 2015). In order to further enhance the quality of the evidence for PBS as a best practice intervention, future research should prioritise larger scale, controlled studies, exploring intervention fidelity, continuing to expand outcome measures beyond challenging behaviour and including service users in research.

# *Chapter 2. “A Better Way of Working”:* Professional Carer Experiences of Implementing Positive Behaviour Support for Adults with Intellectual Disabilities

## Abstract

Best practice guidance recommends Positive Behaviour Support (PBS) in Intellectual Disability (ID) services where people present with challenging behaviour. Despite this, appropriate use of PBS within ID services is considered limited and a theory-practice gap exists between what is known about effective support and what is practiced. Research into the under-utilisation of evidence based practice in healthcare emphasises the need to understand difficulties experienced within the specific context, in order to develop more effective strategies for change. At present, there is little research looking specifically at implementing PBS in this population.

This grounded theory project aimed to explore the experiences of staff implementing PBS in three NHS-run social care homes for adults with ID. Semi-structured interviews were held with thirteen participants with a range of professional job roles. Six theoretical codes emerged from the collected data and are presented in a theoretical model. The codes included: (1) being right for the job; (2) having the right tools for the job; (3) being supported; (4) implementing PBS; (5) reinforcing the use of PBS; and (6) taking time. The developed model allows for guidance and recommendations to be provided to services for implementing and sustaining the use of PBS.

## Introduction

Positive Behaviour Support (PBS) is an evidenced based, person centred framework that aims to improve the quality of a person’s life by promoting inclusion, choice, participation and opportunity. PBS has been shown to be an effective approach for supporting individuals with challenging behaviour, by reducing the need for restrictive practices and increasing positive behaviours (Carr et al., 1999; LaVigna & Willis, 2012). Furthermore, recent policy changes have led to a drive to implement PBS in Intellectual Disability (ID) services and it is now included in best practice guidance where service users present with challenging behaviour (British Psychological Society & Royal College of Psychiatrists, 2016; NHS England, 2017; NICE, 2015). However, the use of PBS in social care settings for adults with ID is considered limited (Emerson et al., 2000; MacDonald & McGill, 2013). Attempts have been made to close the gap between the theory of PBS and its practice in some settings, predominantly schools. However, there is little literature investigating implementation, and associated processes, of PBS in social care settings for adults with ID. Understanding of organisational processes specific to these settings would lead to recommendations for implementing PBS, which would benefit both services and service users.

### Positive Behaviour Support

PBS is a flexible multi-element framework that can be applied to a number of conditions, including ID and Autism Spectrum Disorders (ASD), with people with challenging behaviours (LaVigna & Willis, 2005) and across educational, health and social care settings (Hassiotis et al., 2014). It combines tools of behavioural intervention with individual values, whilst emphasising inclusion in community, participation, respect, improved relationships and skill development (Allen, 2009). It comprises a comprehensive functional assessment of the behaviour and an individualised behaviour support plan, which includes ecological strategies, skill development, focused support and reactive strategies. It focuses on a lifespan perspective, emphasising prevention and stakeholder participation (Hassiotis et al., 2014). Although PBS is primarily a behavioural approach, its inclusive nature allows for influences to be drawn from behavioural, educational and ecological practices, whilst acknowledging the importance of gene-behaviour relationships and the role of internal states and drives (Allen, 2009). Furthermore, Skelly (2016) incorporates attachment and trauma informed care into a PBS framework which further demonstrates the inclusivity and holistic nature of PBS.

PBS rejects the use of aversive or unnecessary restrictive interventions and instead focuses on changing antecedent conditions that are likely to trigger challenging behaviour, skill development as alternative to challenging behaviour and the use of differential reinforcement to develop more adaptive and effective behaviours for satisfying the function of the original behaviour (Allen, 2009; LaVigna & Willis, 2012). A key outcome of PBS is that the use of challenging behaviour is reduced, whilst also emphasising improvement in quality of life (Lavigna & Willis, 2012). It enhances community integration and emphasises service user involvement and choice, thereby helping the person to exert control over their environment (Hassiotis et al., 2014; Lavigna & Willis, 2012).

### PBS as an Evidence-Based Approach

PBS is considered an evidence-based approach (Allen, James, Evans, Hawkins, & Jenkins, 2005; Carr et al., 1999, LaVigna & Willis, 2012) and is included in best practice guidance where people present with challenging behaviour (British Psychological Society & Royal College of Psychiatrists, 2016; NHS England, 2017). Carr et al. (1999) demonstrated that PBS increases positive and socially desirable behaviours from a modest to substantial degree. LaVigna and Willis (2012) carried out a selective review of PBS and concluded it is effective at reducing severity and frequency of challenging behaviour, does not have to be used by specialist clinicians, is cost effective and can be successfully applied in both community and institutional settings. Furthermore, MacDonald and McGill (2013) reviewed the effects of PBS training on outcomes for both staff and service users. They reported that all studies that included a measure of challenging behaviour found a significant reduction in this domain following staff training that focused on the development and implementation of PBS frameworks.

Despite the evidence and inclusion in best practice guidance, a theory-practice gap exists between what is known about effective support and what is practiced in ID services (Campbell, 2010). Given the evidence based approach to service delivery in the UK, it would be expected that PBS interventions would be the most commonly used forms of support, however PBS continues to be underutilised in practice and use in ID services is considered limited (Allen et al., 2005; Carr et al., 1999; MacDonald & McGill, 2013; McGill, Bradshaw, Smyth, Hurman, & Roy, 2014; Shepard, 2012). In 1987, Emerson and Emerson estimated that only half of service users in need of PBS may be treated at any one time with this approach and its use remains limited, with a more recent study finding that of 500 people with ID in social care settings, only 15% were receiving any kind of behavioural intervention (Emerson et al., 2000). Furthermore, a review of the literature by Allen et al. (2005) indicated that between two and twenty per cent of individuals in need of behavioural support were actually receiving any. This review included the most basic behavioural guidelines as interventions and therefore this number is likely an underestimate of high standard, multi-component behavioural interventions used in these settings (Allen et al., 2005).

### Implementing Evidence Based Practice

Applying evidence based theory to routine clinical practice is considered “notoriously difficult” (Johnson & May, 2015, p. 1) and this appears to be the case for behavioural interventions, such as PBS (Allen, 2009; McGill et al., 2014). A number of theories have been generated to provide understanding of how organisations make changes to their practice and what can be done to facilitate the process. Kotter’s (2012) eight step model for implementing major change in organisations includes the following stages: creating a sense of urgency and guiding coalition, developing and communicating vision and strategy, empowering action, generating short term wins, consolidating gains and anchoring new approaches in culture. Although these distinct stages are necessary for change, they are not considered sufficient alone. Leadership is the ability to establish direction and align, motivate and inspire people, and is considered vital for producing useful change (Kotter, 2012). Leadership is also considered a make or break quality in LaLoux’s (2014) guide for creating successful and effective organisations. He proposes that implementation of change in organisational cultures is achieved through practice that supports behaviour change, role modelling by colleagues with moral authority and by providing space for people to explore their belief systems and how this fits, or does not fit, with the new culture.

Previous literature into organisational change in healthcare settings suggests that staff having the appropriate skills and knowledge are important factors for implementing evidence based practice. This makes sense when considering the reliance on direct care staff in implementing PBS in practice (Baker & Shepard, 2005). MacDonald and McGill (2013) suggest that a possible reason for the low levels of use of PBS in practice is the lack of skills of staff implementing the approach, which is in line with previous research which shows that staff training in PBS has a positive impact on levels of challenging behaviour (Dench, 2005). Furthermore, McGill, Bradshaw, Smyth, Hurman, and Roy (2014) suggest that the environment in which interventions for challenging behaviour are implemented is important and provide recommendations for how to create ‘capable environments’, which include supporting communication, participation and relationships, having positive interactions and encouraging more independent functioning for service users. At present these recommendations are conceptual and largely based on research in the child ID population.

In a narrative summary of PBS research, Dunalp and Carr (2007) conclude that the underlying mechanisms required for successful implementation and maintenance of PBS are poorly understood and emphasise the importance of further research in this area. Research into the underutilisation of evidence based practice in healthcare has led to an emphasis on acquiring a good understanding of the problem, the target group, its setting and the obstacles to change, in order to develop more effective strategies for change (Grol & Wensing, 2004). As the focus of PBS moves towards larger scales, i.e. system wide implementation, it is important to look at organisational systems and variables that affect the delivery of PBS (Dunlap & Carr, 2007).

Different settings are likely to have specific social structures and processes, and therefore specific barriers and facilitators to change. Research into PBS in juvenile justice settings found that implementation is unique to this setting and an overarching theme was ecological congruence (Houchins, Jolivette, Wessendorf, McGlynn, & Nelson, 2005). Investigation into implementation of PBS has predominantly taken place in educational settings and there is little literature investigating implementation and associated processes of PBS in social care settings for adults with ID, which differ to school settings. Kincaid, Childs, é, and Wallace (2007) found the following variables to be influential to successful implementation of PBS in a school setting: ‘integration into school’, ‘student buy-in’ and ‘academic-behaviour relationship’. These specific variables are unlikely to be directly applicable to implementing PBS in social care settings for adults with ID, however ideas and broader concepts found may be transferable and further investigation would lead to better understanding of the processes involved in this specific context.

Woolls, Allen, and Jenkins (2012) recognised this need and explored the views of direct care staff and behaviour consultants on implementing PBS frameworks with adults with ID. They also looked at the relationship between these two groups. Five concepts emerged from their data, which were ‘service delivery’, ‘external support’, ‘internal support’, ‘mediators’ and ‘delivery of PBS’. They combined these concepts into a model which puts ‘goodness of fit of PBS’ at the centre and suggest that the five core concepts influence this central idea. Since this study, a drive towards the use of PBS continues to be emphasised, with it now being included in best practice guidelines (NICE, 2015). A major criticism of this study was that the researchers were affiliated with the services where recruitment took place, which may have influenced the data collected. Furthermore, the emerging theory was not validated with participants for accuracy and credibility. Although interpreter bias is inevitable to some degree in qualitative studies (Charmaz, 2014), attempts to reduce this would lead to more credible and valid findings and therefore, it is recommended that further studies in this area include this process. Furthermore, given that recent policy changes and drivers have been implemented to encourage the use of PBS since the time of this study (NHS England, 2017), it would benefit the field to develop a clearer understanding of the implementation of PBS within the current context, with a particular focus on the direct care staff.

### The Present Study

Organisational change is considered a difficult feat and a clearer understanding of organisational variables that influence successful implementation of PBS strategies is required in order to promote its use in practice (Dench, 2005; Allen, 1999). Campbell (2010) stated that a better understanding of what supports implementation of PBS would lead to more successful implementation of the approach and a greater use of PBS would lead to the development of better services for adults with ID and challenging behaviour (Allen et al., 2005).

Although existing theories provide some guidance for how to best undertake organisational change generally (Kotter, 2012; LaLoux, 2014), the literature regarding implementation of PBS has primarily focused on children in educational settings. Given that these settings vary considerably to adult social care settings, it is proposed that further research exploring implementation of PBS in this specific context would lead to a better understanding of organisational processes involved in implementation. Therefore, this project aims to explore the organisational processes experienced by professional carers when implementing PBS within social care homes for adults with ID.

## Method

### Research Design

This study employed a cross-sectional qualitative design. Constructivist grounded theory was used to guide recruitment, semi-structured interview development and analysis of the data. This approach allows the researcher to interpret and explore implicit and explicit themes which emerge from the data and has a focus on the participants’ experience as well as the language used (Charmaz, 2008). This differs from classical Grounded Theory which takes a more realist approach and has little interest in experience and interpretation (Charmaz, 2008). This approach fits with the research question being asked and the epistemological standing of the researcher.

Thirteen staff members employed across three social care homes for adults with ID were interviewed. From the findings, a model for implementing PBS in practice was generated.

### Participants

Participants were recruited from three NHS-run social care homes. The study aims and procedures were explained to the home managers and staff teams. Home managers and senior staff then identified staff members with an interest in taking part. A full explanation of the study was given to these individuals by the researcher, along with a Participant Information Sheet (Appendix 4), and all of them agreed to take part. Many of the staff members had extensive experience of working in care settings (ranging from 3 to 29 years). Eight males and five females were recruited. Participant ages ranged from 30 to 65 years old. Details of staff demographics can be found in Table 4.

### *Table 4: Participant Demographic Information*

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| P | Age | Gender | Job Role | Time in Current Role  (Years) | Total Time in Care  (Years) | Relevant Training  (in addition to mandatory PBS training) | Use of PBS  (Years) |
| 1 | 48 | F | Deputy Manager | 3 | 29 | PMVA | 4 |
| 2 | 52 | M | Staff Nurse | 3 | 3.5 | PMVA | 3 |
| 3 | 65 | M | Senior Support Worker | 2 | 15 | PMVA, Breakaway, Autism training | 2 |
| 4 | 41 | F | Senior Support Worker | 3 months | 13 | PMVA | 3 |
| 5 | 60 | M | Care Assistant | 2 | 15 | Maybo | 15 |
| 6 | 36 | M | Staff Nurse/Clinical Lead | 2 | 10 | Maybo, Clinical Risk Assessment | 2 |
| 7 | 37 | M | Support Worker | 5 | 15 | PMVA, Maybo | 5 |
| 8 | 59 | M | Care Assistant | 4 | 24 | Maybo, Autism Championship | - |
| 9 | 53 | F | Senior Support Worker | 19 | 28 | Maybo | 1 |
| 10 | 30 | M | Activity Coordinator | 1 | 3 | PMVA, Understanding Autism | 3 |
| 11 | 62 | M | Support Worker | 6 | 23 | Maybo | 3 |
| 12 | 52 | F | Support Worker | 13 | 13 | Maybo | 2.5 |
| 13 | 44 | F | Registered Manager | 4 | 23 | Challenging Behaviour training, ID Nursing training | 4 |

*Key and Additional Information: PMVA - Prevention Management of Violence and Aggression), Maybo Conflict Management Training.*

#### Inclusion criteria

* Paid employees working within one of three social care homes run by the identified NHS Trust.
* All participants had received the mandatory online PBS training required by the service.
* Good spoken English to ensure participants could fully engage in the interview.
* Bank staff employed by the trust who had worked in the service on at least a weekly basis for a minimum of 3 months and met inclusion criteria were included.

#### Exclusion criteria

* Staff working in the service for less than 3 months.
* Ad-hoc/temporary staff with intermittent experience of working within the service, for example bank or agency staff.

Temporary staff or staff new to the service were less likely to be able to comment on their experiences of implementation or how PBS has been sustained over time, and therefore were excluded.

### Data Collection

#### Questionnaires

In order to situate the sample, participants were asked to complete a demographic questionnaire (Appendix 5). Furthermore, home managers were asked to complete a service related questionnaire in order to obtain information regarding the service context (Appendix 6). Demographic information for participants and services can be found in Tables 4 and 5 respectively.

### *Table 5: Service Demographic Information*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Service | PBS Implemented | Service User Demographics | List of Service User Diagnoses | Summary of Challenging Behaviour Displayed |
| 1 | 2015  Over a 3 year period | 5 Males  Aged 50-60 | Severe ID  Autism  Pica  Bipolar Disorder  Epilepsy  Polydipsia | Physical aggression  Pica  Refusal to allow peg feeding |
| 2 | October 2017  Over a 2 month period | 5 Females  Aged 43-64 | ID  Autism  Epilepsy  Physical Disabilities | Physical aggression  Screaming  Falling to the floor  Removal of clothes in public areas  Inappropriate urination  Repetitive question asking |
| 3 | 2014  Over an unknown period | 7 Males  Aged 25-70 | Moderate to severe ID  Autism  Epilepsy  Mobility issues  Bipolar Disorder  Pica  Fragile X | Violence and aggression  Ritualistic behaviour  Pica  Verbal aggression  Property damage |

#### Interviews

Data was collected via audio recorded, face to face semi-structured interviews. All interviews took place in private rooms within the service in which the participant worked. The interview schedule was developed by the researcher and reviewed by the project supervisors. Questions were focused on areas such as the participants’ understanding of PBS, their feelings towards it, the challenges in implementing PBS and if and how these were overcome. Facilitative processes were also explored along with participants’ views on how they were supported through the process of PBS implementation. Example questions included in the initial interview schedule are:

* What is your understanding of PBS?
* How does PBS differ to your previous practice, if at all?
* Did the way you feel about PBS change over time? If so, how?
* What is most helpful in supporting the use of PBS?
* What challenges are there to maintain PBS?

Participants were reassured that the interview was in no way an evaluation or judgement of their work or the service and that there were no incorrect responses to the questions posed. This was to ensure that participants felt as comfortable as possible to discuss difficulties and challenges within the workplace. Observations and thoughts regarding the interviews were recorded by the researcher following the interviews.

Following interviews, feedback was sought from participants in regards to the content of the interviews, how understandable the questions were and the approach of the interviewer. Participants reported generally positive experiences taking part and felt that the questions asked were understandable. Some participants felt that the interview schedule was repetitive at times. However, this repetition was deemed as useful by some, as it allowed them to think further on a particular subject area. As the benefits of this seemed to outweigh the negatives, repetitiveness of the questions was not addressed in subsequent versions of the interview schedule. In line with a Grounded Theory approach, the interview schedule was updated following interviews in order to allow the researcher to confirm and expand on the data collected from previous interviews (Charmaz, 2014). For example, following discussions regarding service users’ family involvement with participants, the following question was added to the interview schedule to explore this: Do service users’ families influence the use of PBS at all? If so, how? Similarly, in response to participants’ identifying difficulties with adhering to PBS plans, a question was added to inquire how able participants felt in doing so. This was followed by prompts to ask participants what makes it easier or more difficult to do so. The final interview schedule can be found in Appendix 7, with all changes highlighted.

### Procedure

Participants were recruited systematically from social care homes for adults with ID. The researcher attended team meetings to provide the staff with an overview of the research project. Participant Information Sheets (PIS; Appendix 4) were also distributed to the staff teams. Once a participant was identified as interested in the project and eligible to take part, further discussions regarding the project and PIS were held between the participant and researcher. Participants were given the opportunity to ask any questions regarding the project and their participation. The researcher gained informed consent by ensuring this information was understood and informing participants of the boundaries of confidentiality, how their data would be stored and they could withdraw at any time. Participants were made aware that the interviews would be audio recorded and that the files would be deleted once the audio was transcribed. Both the participant and the researcher signed two copies of the consent form (Appendix 8), one for each of their records. Once consented into the study, participants were asked to complete the demographic questionnaire. The audio-recorded interview then commenced.

Thirteen interviews took place between 28/09/2018 and 04/03/2019. Interviews lasted between 34 and 57 minutes, with a mean length of 47 minutes. At the end of the interviews, participants were debriefed and provided an opportunity to reflect on their experience of taking part and ask any questions.

#### Grounded Theory

In order to investigate the research questions, a Grounded Theory approach was utilised. This was deemed most appropriate for this project because of its exploratory nature and usefulness in studying phenomenon involving social processes, such as social care settings (Denscombe, 2013). A Grounded Theory approach allows for theory to be generated to account for, and explain, why things happen as they do. In the context of implementing PBS in social care settings, Grounded Theory allowed for exploration of the social processes involved in implementing PBS and generation of theory, which could lead to recommendations for other services looking to implement this change.

#### Sampling and saturation

Theoretical sampling was used to ensure a variety of positions were recruited, e.g. support workers, nurses and managers. This enabled a range of perspectives to be explored and allowed for the sample to be representative of the staff groups working within the homes, which include a mixture of leadership positions and front line staff. Reflection of this process allowed for purposeful recruitment in order to explore emerging themes from the data. For example, the first four participants to be recruited were in senior positions and therefore the researcher sought more junior roles, such as care assistant and support workers, for recruitment to enhance heterogeneity of the sample. In addition, a common theme throughout the data was related to leadership and the importance of this for implementing PBS. As a result, a home manager was specifically targeted for recruitment in order to explore this from their perspective. This mix of staff enhanced heterogeneity amongst the sample, in keeping with Grounded Theory.

Grounded Theory stipulates that data collection should continue until theoretical saturation is met, i.e. when no new information is observed in the data (Charmaz, 2014). Little guidance exists in regards to adequate sample sizes required for theoretical saturation. Guidance can be sought through identifying Grounded Theory research within similar fields, however this is not definitive. Due to the relatively small sample size in the current study, theoretical saturation may not have been reached, however enough data was collected in order to construct a coherent theory and therefore data can be considered theoretically sufficient (Dey, 1999).

### Analysis

#### Transcription

The audio files were transcribed verbatim by the researcher. This allowed them to immerse themselves in the data and enhanced their understanding and awareness of the themes and ideas raised by participants.

#### Coding and memos

Coding is the process of actively processing and naming the collected data, whilst defining what is happening within it (Charmaz, 2014). The first stage is initial coding, where individual segments of data are closely analysed and given a name. The researcher used line by line coding to ensure that the data was thoroughly and closely analysed. During this stage of coding it was important to ensure the researcher stayed as close to the data as possible. This was enabled by using the participant’s own words to name the codes wherever able. Coding is then developed to become more focused. This focused coding stage involves synthesising initial codes and allows the researcher to begin to make links between them, leading to more condensed and specific codes (Charmaz, 2014). At this stage of development it is important to look out for processes and phenomena that participants are alluding to without directly describing. The researcher then begins to develop higher order conceptualisations of the data.

Finally, theoretical coding allows the researcher to develop a theory which is grounded in the raw data. During this phase, the researcher begins to highlight the relationships and interactions between focused codes. Reflective notes, referred to as memos, were kept by the researcher throughout the entire coding process. At this final stage of coding, memos are reviewed as a means of promoting in-depth engagement with the data, aiding exploration of ideas and supporting development from focused to theoretical coding (Birks, Chapman, & Francis, 2008; Charmaz, 2014). Subsequently, a grounded theory begins to emerge and this is incorporated into a diagrammatic model. Samples of coding and theory development at all stages were reviewed by the project supervisors and feedback discussed. This ensured credibility, coherence and applicability to the data. Extracts of transcripts, the coding stages and researcher’s memos are provided in Appendices 9 and 10.

#### Consultation of the developing model

In order to aid development of the model and further ensure credibility, coherence and applicability, the initial analysis and developing model were presented to three staff members from the services where recruitment took place and a psychology service within a local community team for adults with ID. Overall, the model received positive feedback in regards to comprehensibility and relevance. Individuals consulted with found it to be reflective of their experiences both in terms of front line staff implementing PBS and clinicians whose role often involves supporting staff with implementation. Details of the development of the model based on consultation and discussions with project supervisors can be found in Appendix 11.

**Quality Assurance**

The concept of evaluating qualitative research is much debated within the community, with some members holding the view that it is not possible or desirable due to the risk that doing so would constrain an interpretative, intuitive and flexible process (Spencer & Ritchie, 2012). However, it is generally agreed that central principles pertaining to qualitative research can guide good practice and quality assessment should be tuned to the particular qualitative methodology used. In order to maintain quality standards, the research adhered to qualitative research guidelines (Elliott, Fischer, & Rennie, 1999; Spencer & Ritchie, 2012).

In order to enhance the credibility of the findings, it was important to demonstrate the links between the data and the conclusions made (Spencer & Ritchie, 2012). Direct quotes are used throughout this report to demonstrate how the theory has emerged from the data and an extract of transcription and the coding process can be found in Appendix 9. Extensive memos were kept in order to ensure owning of the researcher’s perspective and extracts of these can be found in Appendix 10. In order to situate the sample and provide clarity on the context within which data was collected, demographic information regarding the participants and the services is presented in Tables 4 and 5 respectively (Elliott et al., 1999). This also allows the reader to assess the applicability of the findings and the rigour and thoroughness by which the data generation process was conducted (Spencer & Ritchie, 2012).

Frequent discussions with project supervisors and consultation with a selection of staff members from the recruited services and a local community team for people with ID demonstrates quality standards pertaining to credibility, validation, coherence and resonation with readers (Elliott et al., 1999; Spencer & Ritchie, 2012). Furthermore, the data is presented in a way that represents the experiences of the participants, by using their language to name codes and concepts wherever appropriate, further enhancing the likelihood the research will resonate with readers (Elliott et al., 1999).

Due to their specificity, the conclusions drawn from this research project apply only to the context studied. Limitations of extending the findings to other instances will be discussed further in the discussion section. Discussion of methodological limitations and further research gaps are also identified throughout this report in order to demonstrate the extent of the project’s contribution to knowledge (Spencer & Ritchie, 2012). The project aimed to have a real world impact on the lives of adults with ID. The findings from this project will be translated into recommendations for staff and services to utilise in order to promote the use of PBS and ultimately enhance the quality of life of individuals it is used with.

Throughout this project, decisions and actions taken were discussed with the project supervisors and are documented throughout this report. Key documents used are included in the appendices in order to aid transparency for the reader, i.e. the interview schedule, PIS and consent forms. Rationale for the methodology used, namely constructivist grounded theory, is provided in order to demonstrate the rigour of which the approach is applied. In addition, consideration of other methods and why these were not appropriate for the research question is described (Spencer & Ritchie, 2012),

***Reflexivity***

Given the subjective nature of many research processes involved in qualitative projects, it is important for the researcher to be reflexive of their own preconceptions, interpretations, beliefs and values, and their potential impact on the research processes (Charmaz, 2014). Furthermore, clarity and transparency of the reflexive process, including the values and assumptions that guided the process, are also important to demonstrate rigour (Spencer & Ritchie, 2012). As such, the following disclosure is provided to readers: As the researcher for this study, I am a 29 year old, white, female Trainee Clinical Psychologist. My work experience prior to doctoral training was as a Support Worker in social care settings for people with ID and also as an Assistant Psychologist within a community team for individuals with ID. Through these roles I gained experience of implementing behavioural support plans both on the ground as front line staff and also as a clinician whose role was to support the development and implementation of behavioural support plans in social care settings. These experiences helped me to have an understanding of these contexts and the roles of the staff recruited. In addition, I have experience of seeing PBS work effectively in practice and hold a position of valuing PBS as a framework for working with individuals with ID. Throughout this research, it was important to keep these experiences and positions in mind, and consider how they might contribute towards the way that I interpret and understand the emerging data. Memo-writing was also used to allow the researcher to keep track of the analytical process (Elliott et al., 1999; Spencer & Ritchie, 2012).

### Ethical Approval

Full ethical approval was gained from the Health Research Authority (HRA) and Royal Holloway University of London Research Ethics Committee (REC). Confirmation of approval can be found in Appendices 12 and 13 respectively.

#### Ethical considerations

In line with quality assurance guidelines for qualitative research, ethical implications of the project were carefully considered and sensitivity towards the research context and participants was demonstrated (Spencer & Ritchie, 2012). Although the planned interview questions were not deemed to be of a sensitive or personal nature, it was not known prior to interviews whether participants were going to have experienced difficulties in the workplace which may have led to feelings of distress if reflected upon as part of the interview process. The researcher was considered adequately trained to support them if distress were expressed, although this was not the case for any participants and it was not necessary to terminate any interviews early or signpost participants to additional support. Confidentiality and anonymity were also carefully considered to ensure participants felt comfortable and able to talk openly and honestly about their experiences.

The interviews took place in settings that were homes to the residents living there. Therefore, it was important to ensure that the interviews did not cause any distress or disturbance to their wellbeing and the level of care provided. Had any service users demonstrated distress at the researcher’s presence, interviews would be postponed and alternative arrangements would have been made, however this was not necessary over the course of the interviews.

## Results

Data analysis identified six theoretical codes that together, form the proposed theoretical model. Nineteen focused codes were identified. These are shown in Table 6, along with samples of initial codes. The theoretical codes have been incorporated into a diagrammatic model which is shown in Figure 2. Direct quotes from the data are displayed throughout this section in order to demonstrate the origin of the codes and how they are grounded in the data. All identifiable information has been removed from the quotes and participants are referred to by their assigned participant number to ensure confidentiality. The symbol [...] is used when text is removed from direct quotes in order to support the clarity of the dialogue. Text within square brackets represents words added or amended by the author for the same reason.

### *Table 6. Theoretical Codes, Focused Codes and Sample of Initial Codes*

|  |  |  |
| --- | --- | --- |
| Theoretical Codes | Focused Codes | Sample of Initial Codes |
| Being right for the job  N= 13 | Understanding of PBS  N= 13 | Understanding PBS principles  Valuing Training  Developing understanding through training |
| Valuing PBS  N= 13 | Being useful  Seeing PBS as better way of working  Noticing differences between old and new staff |
| Internalising PBS values  N= 12 | Needing the right fit between job and staff  Considering what is needed to work in care |
| Having the right tools for the job  N= 13 | Being in environments that are fit for purpose  N= 5 | Reflecting on how they want their home to be  Thinking environment is very important  Thinking rooms help with giving service user space |
| Having adequate resources  N= 5 | Having to have the facilities  Being short staffed impacts adherence to plans  Having input from external professionals |
| Having accessible plans  N= 11 | Being easier to remember plans that are clear and simple  Getting team’s input in plans  Having ownership over plans |
| Being supported  N= 13 | Promoting staff wellbeing  N= 5 | Keeping staff safe  Knowing what you are allowed to do to look after yourself  Seeing working in a positive way as good for the mind |
| Making PBS mandatory  N= 8 | Being told to read through plans  Having to do the training  Having to use PBS when they came to work here |
| Creating a supportive work culture  N= 8 | Being open to feedback  Being able to talk with the manager  Feeling senior staff are approachable  Being listened to |
| Working as a team  N= 10 | Supporting each other  Not letting other staff struggle  Communicating with each other |
| Being reflective  N= 7 | Reflecting on how to do it better  Reflecting whilst travelling home  Valuing reflection  Seeing themselves in service users |
| Implementing PBS  N= 13 | Needing to experience PBS in action  N= 5 | Thinking about PBS being something you read on paper  Not fully knowing situation until you are in it.  Leading by example  Needing to give it a go |
| Having good ways of working  N= 11 | Putting good ways of working into a plan  Seeing PBS as a guideline for everyday behaviour  Seeing benefit of PBS is consistency  Taking positive risks |
| Developing positive relationships between staff and service user  N= 11 | PBS leading to harmonious relationships  Thinking about working with service user and them working with you |
| Reinforcing the use of PBS  N= 12 | Seeing results  N=8 | Seeing benefits reinforces use of PBS  Reducing incidents  Thinking PBS has worked to reduce restraint  Helping to settle service users |
| Having a sense of job satisfaction  N= 8 | Picking up positive feedback from service users in their responses  Thinking feedback can only have a good impact  Thinking praise going a long way  Wanting to do a good job |
| Taking time  N= 12 | Becoming easier with time  N= 8 | Seeing PBS as ingrained because they use it daily  Finding it hard to kick start PBS at beginning  Finding PBS more challenging at first  Growing confidence with experience |
| Seeing change to practice over time  N= 11 | Not getting proper support before PBS  Thinking service users get more respect from all staff now  Taking time to refer to behavioural support plans more  Moving away from institutions |
| Changing attitude towards PBS over time  N= 6 | Seeing new documents as less important  Moving away from doubts about PBS  Changing opinion of PBS over time |

### Theoretical Code 1: Being Right for the Job

#### Understanding PBS

All participants demonstrated a good understanding of PBS principles. This seemed to come from training in PBS, which was highly valued by participants.

*‘I think when I did the training it was good. I think it has actually helped [...] my knowledge and understanding of erm… the training has actually helped me in er supporting the gentlemen’ (P2)*

#### Valuing PBS

All participants spoke highly of PBS and valued its effectiveness, safety and usefulness. There was recognition that when PBS is first implemented, there is a difference in how longer serving staff and new staff members value PBS, with longer serving staff being initially more resistant to change.

*‘I don’t feel institutional, and I think like erm, I’ve seen a lot of changes, and I think this is like erm, seems like a good way of working’ (P1)*

*‘It is a way forward’ (P7)*

#### Internalising PBS values

All but one participant demonstrated an alignment between their own values and PBS values. There was consideration for what was needed as an individual to work in care services, and often this was demonstrated through the way participants spoke about service users.

*‘Proactively support them in a positive manner so that you can help with the behaviour and make it err make it life worth living for them’ (P2)*

### Theoretical Code 2: Having the Right Tools for the Job

Working with the right tools and resources, within appropriate environments allowed them to put PBS into practice. Staff described times when these practicalities were not available and how this impacted on their practice and subsequently, the wellbeing of the service users.

*‘I was quite short [staffed] last year a little bit, for a good four, five months, so basically there was some impact, you could observe some slight changes in their mood erm, so you will notice it’ (P13)*

#### Being in environments that are fit for purpose

Some participants identified the importance of the environment being fit for purpose. This was in terms of making sure there was enough physical space to support behavioural support plans and service user safety, and also in terms of making the environment homely. Specifically, participant 13, a registered manager spoke about making changes to the environment to make it more fit for purpose.

*‘Making the place itself cosy and warm with the colour [...] you know it’s the same thing as me as well, when I go home, I want my home to be clean, I want my home to be nice colour and it’s make you feel happy, so we’ve changed everywhere like that, (P13)*

#### Having adequate resources

A number of participants reported that having the right resources and facilities supported the use of PBS. This included reporting the need for adequate staffing levels and experience, and identified that new staff and agency workers can impede adherence to behavioural support plans. There was also acknowledgement that having input from external professionals could be helpful in providing fresh and alternative perspectives.

‘*You’ve got to have the facilities to, to doing it […] you need the right amount of staff as well cause each person needs quite intense erm support’ (P1)*

#### Having accessible plans

Most participants reported the need for accessible behavioural support plans. Having plans that were simple, to the point and therefore easier to remember facilitated adherence to working within a PBS framework. In addition, PBS was facilitated by teams being involved in the plan development, as this led to them being more on board with them and hence making them more likely to follow them. Some participants also referred to needing explicit awareness of who was responsible for reviewing and updating the plans, in order for them to feel comfortable doing so.

*‘it’s a lot more in detail so that is getting a bit difficult to remember as well, yea, if it’s you know, clear and simple and you know, then it would be easier for, to remember, for all of them’ (P4)*

*‘And also it doesn’t work if the team don’t own it’ (P1)*

### Theoretical Code 3: Being Supported

#### Promoting staff wellbeing

Some participants spoke about the wellbeing of staff in terms of keeping safe and looking after themselves at work. It seemed like PBS was valued due to its indirect positive impact on staff safety, which facilitated its use. There was also recognition that working within a positive framework was good for staff morale, which was likely to also facilitate positive practice.

*‘I think it helps all of us if we work in a positive way, I think it’s good for everyone’s mind, if you’re all frustrated, then erm, and erm negative, that’s just gonna impact on everyone’s morale’ (P1)*

*‘They would come in and sit with me, say okay do this, do that […] if it’s too much, you can’t take it, just step, step outside for a while [...], there’s things that you don’t, sometimes you don’t know you’re allowed to do [to look after yourself]’ (P8)*

#### Making PBS mandatory

Eight participants spoke about PBS being mandatory; this included a range of senior and junior staff. This seemed particularly facilitative when PBS was first introduced in order to kick start the implementation of the framework.

*‘Erm actually when I came here, you had to do the PBS’ (P12)*

*‘But whether they like it or not I said you’ve got to do it, it’s your duty’ (P13)*

#### Creating a supportive work culture

Eight participants referred to the impact of the work culture on their everyday practice. It seems that a work culture where staff feel comfortable approaching management, are open to feedback and feel listened to facilitates a feeling of being supported.

*‘You can actually ask any sort of question, you’re not, you’re not held back to ask certain things, and you go on a first name basis’ (P3)*

*‘Like I mentioned before it’s about involvement, it’s about keeping your team happy, it’s about communicating with them erm all the time, it’s about leaving like an open door policy, I never shut my door’ (P13)*

#### Working as a team

Most participants reflected on the impact of team work on their use of PBS, and this was facilitated by good communication and trust amongst the teams. Supporting each other was seen as an important factor for team work. Team work was then seen to further facilitate consistency in approach amongst the team.

***‘What helps the team to work well together?*** *Well I think trust of course, trust in each other’ (P3)*

*‘if everyone is reacting the same way to something then it helps that person to understand, you know what’s going to be expected, [...] it helps everyone to have a consistent approach’ (P6)*

#### Being reflective

Seven participants spoke about being reflective. At times this was explicitly spoken about in terms of thinking about what went well and what they could do differently in supporting service users. There was also an implicit reflective process underlying many conversations, whereby staff saw themselves, family members or friends in service users and their situations.

*‘I think erm benefits [of PBS] maybe is to just help you reflect on how you do your work, and maybe just look erm and think about if I do better next time, [...] maybe add something, take something away’ (P11)*

*‘They can choose what they want to do, if they don’t want to do that set, like timetable as such, because I know myself I don’t always want to do like go out every night, so if they don’t want to go out then they are free to say no and they’re listened to’ (P10)*

### Theoretical Code 4: Implementing PBS

#### Needing to experience PBS in action

Some participants identified that reading about PBS and individual behaviour support plans was not enough to implement it. This was also emphasised by senior staff who spoke about leading by example and modelling good practice in order to promote the use of PBS.

*‘It’s something you read on paper but you don’t even know until you meet the actual situation, you can’t understand, [...] so that’s how you see the difference between reading and practice’ (P8)*

*‘it’s just a question of setting good examples yourself and showing people the right way of doing something, [...] yea you have to lead by example a little bit’ (P1)*

#### Having good ways of working

The majority of participants spoke about PBS providing them with strategies and ways of working, which helped them make use of it in practice. PBS was seen as providing helpful guidelines for how to work with people and by doing so, supported a consistent approach to service users which is considered beneficial.

*‘I feel it’s a good thing, it’s a good guideline, it’s a good way of er, having, information’ (P9)*

#### Developing a positive relationship between staff and service user

Nearly all participants identified the importance of staff getting to know service users and reciprocally service users getting to know staff. As their relationships developed, participants reported feelings of trust between them and service users. It seemed that this process was facilitated by PBS, whilst also facilitating the use of PBS.

*‘Using the PBS there will be a harmonious relationship [...] between the carer and… I find it, as simple as that’ (P5)*

### Theoretical Code 5: Reinforcing the Use of PBS

#### Seeing results

Eight participants spoke about the positive results of PBS and how this reinforced its use, despite any initial doubts or resistance towards it. The results identified included reduced incidents and use of PRN medication or restraints, and improvements in service users’ mood and wellbeing.

*‘If I see that it’s for the benefit of the gentlemen, then I’m willing to go with it’ (P1)*

#### Having a sense of job satisfaction

Many participants alluded to gaining a sense of job satisfaction from using PBS, which further reinforced its use. Participants spoke about getting positive feedback from both senior staff and service users as rewarding. They also expressed wanting to do a good job and that they saw PBS as a way of achieving this.

*‘Because you want them to trust you in a way, so that in the end, how you have worked like, you get it, work satisfaction, yea, so remember it’s trust, you are, you are able to fulfil your duty’ (P9)*

### Theoretical Code 6: Taking Time

Implementation was experienced as a process which takes place on different levels, including the individual staff practice level, staff attitudes towards PBS and organisational change. As with many processes, this was considered to take time and to be ongoing.

*‘With practice and with time, they’ve improved themselves, they’ve read it and erm they’ve [gotten to know] the guys’ (P13)*

#### Becoming easier with time

Eight participants referred to the use of PBS getting easier over time. This was attributed to it becoming an automatic response as staff became more experienced and confident in implementing it.

*‘Yea it’s almost like muscle memory, [...] I think because I’m using it daily that it’s ingrained and I don’t have to think about it’ (P10)*

*‘We don’t have to go and check the plan or oh we do this or we do… it comes automatically’ (P9)*

#### Seeing change to practice over time

Most participants identified that there had been a shift in practice over time. This refers to services generally moving away from institutional settings and towards service users receiving better support, particularly in terms of being viewed as an individual, being supported to make choices, being more involved in their own care and increased opportunities to expand their experiences. There was also reference to a change in the way that staff relate to service users, with this being less hierarchical and more respectful than previous practice.

*‘Because the whole place was erm in a kind of a turmoil****,*** *people were not always settled, [...] I believe people were not getting, I mean, hindsight, made me then realise that no, people are not getting the proper support [before PBS]’ (P2)*

*‘[It’s about] treating each person individually, seeing how you can best support that person in like everyday life so that they, their daily experience is like is is tailored to them’ (P1)*

#### Changing attitudes towards PBS over time

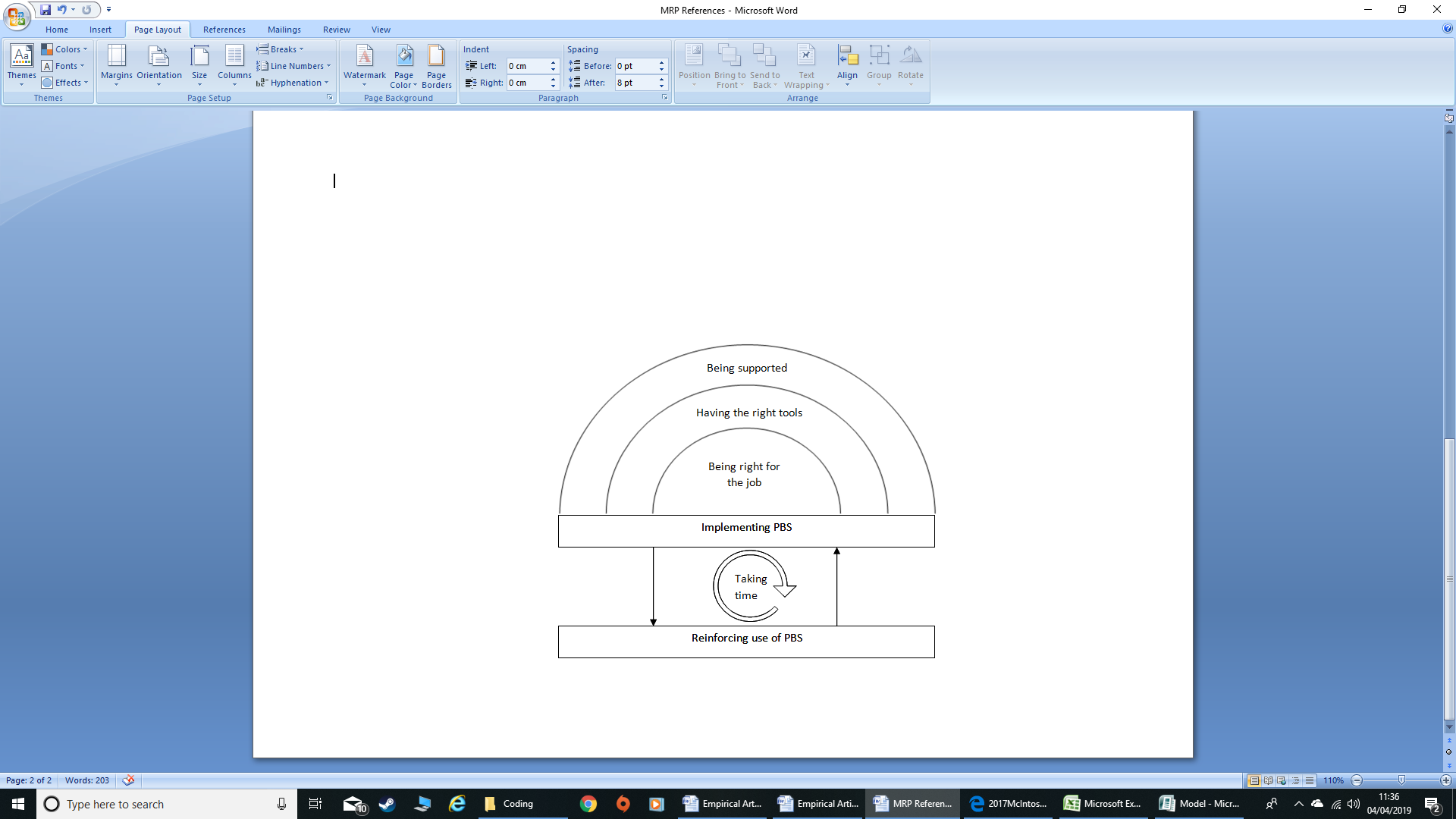
Nearly half of the participants also identified a positive change in staff attitudes towards PBS over time. This shift led to reduced doubts in the use of PBS and to seeing it as an important way of working with service users.

*‘You still have [resistance], I’m not saying that you don’t have it, you still have little bit in there, they won’t tell you but I feel it’ (P13)*

*‘I didn’t really pay it any attention, I just thought it was another document and I stuck to what I, what I knew, what was working with from the past, erm but yea it has changed’ (P6)*

### Theoretical Model of the Experiences of Staff Members Implementing PBS

Figure 2 shows a diagrammatic representation of the theoretical model of the experiences of staff members implementing PBS in social care homes for adults with ID, which demonstrates how the theoretical codes (written in bold italics here) relate to one another. The diagram shows that in order to support implementation of PBS, there must be a fit between the staff member ***being right for the job*** and the job role. Although all participants valued PBS at the time of interviews, it is important to acknowledge that there was a difference in how longer serving staff viewed the approach initially, with them being more resistant to the change compared to newer staff members. The staff should be provided with the ***right tools for the job***, including resources, adequate staffing levels and appropriate environments, whilst also ***being supported*** by management, the team and the work culture in which they practice. ***Implementing PBS*** is further facilitated by having guidelines for ways of working, experiencing the use of PBS in practice and through developing relationships between staff and service users. Once implementation is initiated, the positive results that follow for the service users and the sense of job satisfaction experienced by the staff members promote a cycle that allows the ***reinforcing use of PBS***. The model also indicates that implementation needs to allow for these processes ***taking time***.



*Figure 2. Diagrammatic Representation of the Theoretical Model*

## Discussion

Implementation of intervention frameworks is considered a complex task (Allen, 2009; Johnson, 2017). This study explored the experiences of staff members when implementing PBS in social care homes for adults with ID. It aimed to explore the organisational processes experienced by professional carers when implementing PBS within these settings. Thirteen staff members were interviewed about their experiences and a Grounded Theory approach was applied to achieve the studies aims.

All participants interviewed demonstrated an anecdotal, good understanding of the basic principles of PBS (e.g. promoting choice, skill development, ecological manipulations, improving quality of life). This is consistent with evidence that suggests having adequate knowledge and understanding of an approach facilitates implementation (Fixsen, Blase, Metz, & Van Dyke, 2013). Although this understanding was attributed to training by many participants, previous research suggests that training and knowledge alone is not enough to facilitate practice implementation (Denne, Jones, Lowe, Brown, & Hughes, 2015; Fixsen, Naoom, Blase, Friedman, & Wallace, 2005). In addition to recognising a development of their understanding through training, participants also identified that needing to experience PBS in action in order to implement the approach. Furthermore, support from external agencies and consultation of new approaches is considered beneficial for implementation (Fixsen et al., 2005). Participants interviewed in this project appeared to appreciate support from external professionals, however this was conditional to staff feeling like their input was also valued. Stakeholder involvement is considered a core component for successful implementation of evidence based practice, however there is little research into how to achieve this (Fixsen et al., 2005). Based on this project, it seemed that requesting staff input in development of behaviour support plans was one way of doing so. All participants expressed positive views and opinions of PBS, which may also support their buy-in to the approach.

Fixsen et al. (2005) provide a detailed review of implementation research. From their synthesis of the literature, they identified a conceptual framework for implementing evidence based practice. This framework identifies a feedback mechanism which they consider an essential component for implementation. This mechanism is twofold and relates to staff receiving feedback through appraisal from management and also through positive outcomes directly observed as a result of the intervention. Both of these parts of Fixsen et al.’s framework are consistent with this project’s findings that job satisfaction and receiving feedback are reinforcing factors. This is in line with research looking into implementation of PBS with children, that also found feedback on the positive outcomes of participant’s efforts to be essential to implementation (Johnson, 2017), and Woolls et al. (2012) study into implementing PBS with adults with ID. Fixsen et al. (2005) also identified three broad categories of factors that influence implementation, which again are consistent with the findings of this study. These include having support to build knowledge, organisational structures that support implementation and leadership that addresses needs of implementers. Their model suggests that the initial stages of implementation is considered effortful, which is consistent with the findings that implementing PBS becomes easier over time. Their review also recognises that implementation is an on-going process, which is consistent with the theoretical code of taking time, identified in this project. These comparisons suggest that Fixsen et al.’s general findings are applicable to the specific context of implementing PBS with adults with ID.

McGill et al. (2014) provide recommendations for creating ‘capable environments’ in which behavioural interventions for challenging behaviour are most likely to be successfully implemented. Although applicable to the ID population, much of the illustrative evidence provided by McGill et al. is from child studies. The current study provides evidence relating to the adult ID population for the following recommendations put forward by McGill et al.: provision of acceptable physical environments, mindful and skilled carers and effective management, support and organisational context, all of which are in line with themes identified in this project.

Practice leadership is a form of leadership that encourages best practice through modelling and use of practical examples by senior staff (Denne et al., 2015). This promotes a feeling of being supported by management and demonstrates an understanding of the reality of their job role. Performance is enhanced through feedback, team discussions and demonstrations by management. Practice leadership was first suggested for use with services for people with ID and is a form of management which has become increasingly utilised (Mansell, Hughes, & McGill, 1994). Many aspects of practice leadership were implicitly identified by participants in this study, including leading by example, receiving feedback and praise and an emphasis on needing to feel supported and valued in the workplace. This is also in line with more general theories of organisational change that suggest good leadership is crucial for implementing change (Kotter, 2012; LaLoux, 2014).

At present there is little evidence into the impact of staff wellbeing when working with individuals with challenging behaviour (Denne et al., 2015). The model developed for this study identified that promoting staff wellbeing aided their use of PBS in the workplace. There is evidence that staff working in these challenging and emotive environments are at increased risk of occupational stress and burnout (Hastings, 2002), which can be detrimental to the quality and functioning of services. Staff stress is known to be a consistent issue in services working with people with challenging behaviour (Woolls et al., 2012), which may also be linked to the often high turnover of staff in these services (Denne et al., 2015). Moreover, evidence is emerging into interventions for promoting staff wellbeing and its impact on intervention implementation. For example, Singh et al. (2016) found that including mindfulness-based exercises in PBS training enabled care givers to manage their stress more effectively than PBS training alone, and led to a reduction in restraints used by staff, aggressive events displayed by service users and staff turnover. Interestingly, the manager interviewed in the current study reported a low turnover of staff in their service and also demonstrated the principles of practice leadership. Further investigation into the relationship between leadership, staff wellbeing and the functioning of services would benefit this field.

Consistent with previous findings that poor quality and complex behaviour support plans are less likely to be effectively implemented (Wardale, Davis, Vassos, & Nankervis, 2018), participants in this project identified overly detailed and complex behavioural support plans as difficult to follow and adhere to. Additionally, having adequate resources, such as sufficient staffing, is essential for staff to implement PBS. These were issues also raised by Woolls et al. (2012) and both studies agree that implementation is aided by communication amongst staff.

Grol and Weinberg (2004) refer to the ‘PRECEDE-PROCEED’ model of implementation in healthcare systems which identifies influences across three levels: (1) pre-disposing (e.g. knowledge and attitudes of implementers); (2) enabling (e.g. resources and capacity); and (3) reinforcing factors (opinions and other’s behaviour). Grol and Weinberg (2004) report that systematic reviews of studies looking into effective implementation have shown that strategies require elements from all three levels in order to be successful. This study identified factors across all three levels reported by Grol and Weinberg (2004), including characteristics of professionals, team functioning, available time, staff and resources, and leadership.

In their qualitative study looking at staff views of implementing PBS, Woolls et al. (2012) identified that feedback, support and involving care staff in change were all influential factors in developing relationships between clinicians and care staff. These were all factors that were considered to influence the implementation of PBS in this project. Furthermore, their category ‘becoming second nature’ is consistent with this study’s theme of ‘becoming easier over time’. In contrast to Woolls et al.’s (2012) study, negativity towards management was not identified in this project, nor was characteristics of service users identified as a stressor. They also stated that staff in social care settings did not feel that PBS being mandatory was a driver towards working within a PBS framework, which is opposing to the current study which identified PBS being mandatory as a facilitative factor for implementing PBS. It may be the case that some of these differences reflect the stage of implementation. The service in this study to most recently implement PBS had done so two years ago, with the other two implementing the change 4 and 5 years ago. Comparable information is not available in Woolls et al.’s (2012) study. They report that four of their eight direct care staff participants were involved in implementing PBS for over a period of one year, but do not provide similar information for the other participants. It may be that the use of PBS was not as well-established in the Woolls et al. (2012) study so challenges may have been more prominent for the participants, whereas facilitative factors were more of a focus for participants in this study, reflective of the longer term and potentially more established implementation of the framework.

There is considerable evidence that participants experience apprehension about how they will be evaluated during scientific studies (Weber & Cook, 1972). Therefore, it is important to consider reservations participants may have had in disclosing challenging or controversial aspects of their workplace during interviews. As previously discussed, Woolls et al.’s (2012) researchers were affiliated with the recruited services, which may have influenced the data collected and this was not the case in the current project. In addition, for this study steps were taken to reduce this bias, by explicitly stating that the researcher did not have a role in evaluating or judging the participant’s work performance or experience, and emphasising confidentiality. As the likelihood of this bias was reduced, it is reasonable to suggest that differences in findings between these two studies is more likely a reflection of differences between participants’ experiences and the services involved, rather than resulting from participants’ apprehension to disclose.

### Strengths and Limitations of Study

This study aimed to address the theory practice gap between the evidence and utilisation of PBS in practice with adults with ID. This study was robust in its application of Grounded Theory methodology in order to achieve this aim. A strength of the study is its use of participant involvement and credibility checks. Feedback was sought on the interview schedule from participants, in order to ensure it was relevant and understandable. Project supervisors provided extensive feedback on coding stages of the analysis and the model development. Furthermore, participants were consulted on their understanding and relatability to the developing model, in order to promote validity and clarity. The study recruited a range of professional roles in line with theoretical sampling suggested by Grounded Theory. This heterogeneity allows the model to be applied at all levels of the services included in this study. An additional strength is the sample size recruited in this project, which is deemed sufficient for a Grounded Theory study (Charmaz, 2014).

A limitation of this study is that the services recruited from were all run by the same NHS trust in the same county of the UK. This reduces the external validity of the findings and means results may not be generalised to services run by other providers, for example charity or third sector services, or to other parts of the country where different values and cultures may be held. Therefore generalisations should be made with caution. Furthermore, the services recruited were those where PBS has been considered to be well established. While this is based on anecdotal information, the findings did show participants to have a good understanding and positive views of PBS. Although these settings were able to provide information regarding what worked well and ways that challenges were overcome, allowing the researcher to gain an in-depth understanding of facilitating factors, it may be that challenges were missed or forgotten about given the current positive state of the implementation. Inclusion of services currently experiencing significant struggles and challenges with implementation may have helped to expand the findings, particularly in terms of barriers faced when implementing PBS. In addition, participants were identified by home managers and senior staff. This could have influenced the selected sample as managers may have prioritised staff who they thought would speak well of the service and as previously mentioned, it was not always clear where the initial idea for participation came from and this was carefully considered by the researcher. This reflects a limitation of the sampling process. In order to combat this, the research attended team meetings and PIS’s were circulated via email to all staff. This was to ensure that as many staff as possible where informed about the study so they could put their interest forward to managers or directly to the researcher, although no instances of the latter occurred. Furthermore, in some instances, managers arranged interviews with staff who had expressed an interest and happen to be available at the same time as the researcher, suggesting a degree of randomness and coincidence would also have impacted on recruitment.

Finally, given the relatively small-scale nature of this project, it is likely that not all themes reached theoretical saturation before recruitment was terminated. However, it was decided that enough common themes and consistency came up in interviews with participants that theoretical sufficiency was at least met, and a Grounded Theory could subsequently be generated.

### Implications for Future Research and Practice

Further research would benefit from exploration of implementing PBS in services run by providers other than the NHS. This would allow results to be more widely generalised. Furthermore, exploration of services at different stages of the implementation process may benefit the field, as it may provide a wider range of opinions and beliefs regarding PBS generally, which may impact implementation of the framework. Research looking at the impact of individual components of this Grounded Theory model would provide further weight to its applicability. For example, an investigation into the impact of practice leadership on the implementation of PBS would provide further support for this as a facilitative process in implementation. Research of this nature would also allow for identification of which components and themes have the most impact on implementation, which would provide information on areas services should prioritise.

The findings of this study also have implications for practice. Best practice guidance recommends the use of PBS in services for adults with ID and challenging behaviour (British Psychological Society & Royal College of Psychiatrists, 2016; NHS England, 2017; NICE, 2015) and services should continue to be encouraged to implement high quality PBS (Allen et al., 2013). This study found that implementation of PBS is achievable and has positive outcomes for both service users and staff in these services. This information could be beneficial to services that are not currently implementing this framework, as the findings may encourage them to do so whilst providing recommendations for how best to go about making the change. The model provides recommendations for cultural approaches, practical considerations and staff fitness for the job role. These recommendations range from service to staff levels, so components across the entire model can be applied to services by a range of staff. For example, it is likely that service managers will be responsible for environmental and resource related recommendations, however front-line staff involved in the development of plans will be responsible for creating them simply and clearly, in order to promote adherence. Findings from this study should be shared with social care homes and external services working within this field, for example community teams for people with ID. This would enable an understanding of how best to implement PBS for the service themselves, and also how external professionals can support services to do so.

### Conclusion

In conclusion, it appears that many themes identified in this study are consistent with previous research, however this study was amongst the first to empirically explore the processes experienced by staff implementing PBS in social care settings for adults with ID. The model generated is able to bring concepts and theory together into a theoretical understanding of implementation in these settings and identifies six theoretical themes: (1) being right for the job, (2) having the right tools for the job, (3) being supported, (4) implementing PBS, (5) reinforcing the use of PBS, and (6) taking time. The theory is grounded in the data and allows for recommendations to be made to enable services to implement best practice frameworks in these settings. Future exploration of this research area is recommended in non-NHS run social care settings, at different stages of implementation and of specific components of the model generated.

## Chapter 3. Integration, Impact and Dissemination

The aim of this chapter is to highlight the researcher’s reflections on the process of undertaking this project, including decision making processes. It will also synthesise and integrate the two pieces of work described and consider the impact the findings and conclusions may have in real world settings. Finally, a dissemination plan will be described to demonstrate how the impact may be achieved.

### Researcher’s Reflections

I first started working with adults with ID seven years ago and this has been in Support Worker and Assistant Psychologist roles prior to training. As part of these role and subsequent placements during training, I have been responsible for implementing PBS, developing plans and supporting staff teams and families to implement these in practice. From my own experience, discussions with colleagues, and review of the literature, it became clear that implementing high quality and effective PBS is a challenge to staff and services. This awareness and interest in this area, along with discussions with the project supervisors, was the starting point for the formation of this project.

A review of the literature revealed a lack of research specifically looking at implementing PBS in community settings for adults with ID and challenging behaviour, a population for whom it is a recommended framework (British Psychological Society & Royal College of Psychiatrists, 2016; NHS England, 2017; NICE, 2015). PBS is considered an evidence based approach but the literature revealed concerns regarding its use in practice, without much exploration into this specific area. This disconnect between the evidence and difficulties with implementation was of interest to me and an area I wanted to explore further through the empirical piece of this project. In addition, despite PBS being considered an evidence based and NICE recommended guideline, no recent review of the literature looking specifically at the effectiveness of PBS with adults with ID had been carried out. Therefore, it seemed appropriate to explore the evidence base for this population in more detail as part of the systematic review of this project.

Since the completion of this project, abuse of vulnerable adults with challenging behaviour at Whorlton Hall, a hospital setting for adults with ID and developmental disabilities, has been revealed by Panorama (Plomin, 2019), mirroring the exposure of abuse at Winterbourne View eight years ago (Chapman, 2011). Despite the scandal at Winterbourne View being a significant indication of the need to change the way people with ID are supported and cared for (NHS England, 2017), Whorlton Hall demonstrates a pervasive unmet need for good quality care and support, with a basis in human rights and person centred values, such as PBS. On reflection, this further enhances the importance of research such as the empirical project, as development in the understanding of how to implement and sustain good quality care is essential for these vulnerable individuals.

#### Systematic review

In order to conduct a high quality systematic review, it is important to get a good breadth of articles whilst also being specific in the search terms. In order to achieve this, the search terms were adapted and amended multiple times whilst checking that important and well known studies which I was aware would meet the inclusion criteria, were appearing in the search results. Due to the varied and individualised nature of the PBS framework, it was difficult at times to determine whether studies were appropriate for inclusion or not. Any intervention which included an assessment informed, multi-component behaviour support plan was included to ensure that behavioural interventions that met the criteria for PBS, but were not named as such, were included. In order to ensure consistency in study selection and reduce bias for this criteria, the research assistant working on this project was asked to review all of the studies found in the search, rather than a proportion of studies which is more common practice. This, along with the other reliability checks conducted by the research assistant, strengthens this systematic review. Despite this, only two databases were searched and it is possible that journals containing relevant articles were missed due to them not being indexed on the chosen databases searched. Had time and resources permitted, manual searches of any journals which were deemed relevant would have increased the scope of this review and led to more thorough conclusions.

One amendment to the initial inclusion criteria was regarding the inclusion of interventions applied only to employment settings, rather than solely focusing on social care settings, therefore encompassing all community settings for adults with ID. Had studies been found that implemented PBS in other types of community settings, such as day centres, they would also have been included, however this was not the case. This decision was made to ensure that the already small sample of studies was inclusive of all studies implementing assessment informed, multi-component plans with adults with ID or developmental disabilities and challenging behaviour. There is a drive towards adults with ID being supported to enter the workplace (Department for Work and Pensions & Department of Health and Social Care, 2016) and therefore it felt appropriate that studies looking at effectiveness of PBS in this area were also included.

Finally, the systematic review contained only quantitative studies due to the criteria of outcome studies only. Qualitative studies are able to capture a richness and quality of evidence that is not possible in quantitative studies. Due to the individualised nature of the PBS framework, it would lend itself well to qualitative studies looking at individual’s experience of PBS, both from a service user and staff member perspective. Only outcome studies were included in order to look for an overall effectiveness of the framework, however in order to further investigate this area, it would be interesting to include qualitative or mixed method studies in a review.

#### Empirical project

This investigation used a Grounded Theory approach to investigate the research question. In this instance, a qualitative method was justified because the research question is exploratory in nature and was intended to generate an understanding of the social care context in which PBS is implemented. The study explored the experiences of staff members in social care homes when implementing PBS with adults with ID. Grounded Theory facilitates improving understanding of concepts and theories by checking existing ones against new data collected from a specific context (Demscombe, 2013). This fits with the project’s aim to develop understanding of organisational processes and review these against data gathered from social care homes that have implemented a PBS approach. Furthermore, Grounded Theory lends itself well to exploratory research and emphasises discovery. This fits with research that sets out to explore new or relatively under-researched territory, such as implementation of PBS with adults with ID. It is also beneficial when investigating practical activities and routine situations that involve human interactions where individual perceptions are valued (Denscombe, 2013). This allows for generated theory to account for, and attempt to explain, why processes involving human interactions happen as they do. This is preferable to a phenomenological approach (such as IPA) as not only do we aim to investigate staff perceptions and experiences, but aim to generate a theory shaped by the data collected. Similarly, although thematic analysis would allow us to identify, analyse and report on patterns found within the data collected, Grounded Theory requires you to develop and test out emerging theory, for example through theoretical sampling and amending the interview schedule as you go. This allows for arguably more robust and systematic model development, than methodology such as thematic analysis (Howitt & Cramer, 2011).

Throughout the entire development and undertaking of the empirical project, it was important to hold in mind my own perspective and position in regards to PBS. Although I value PBS as a framework, I believe that the experiences I have had of implementing PBS, which involved challenges as well as positives, allowed me to stay balanced when it came to analysing the data. This was important to ensure that all viewpoints were picked up on and valued in the coding process. Furthermore, the services where recruitment took place were all considered to have implemented PBS successfully. This was not formally measured as part of this study, although a good understanding and application of the framework came across in the data collected from all three services. Had more time and resources been available, it would have been interesting to measure the intervention fidelity of these services and how this may relate to the participants’ experiences.

Although the staff population was relatively easy to recruit from, initially I experienced some anxiety about getting recruitment started and ensuring I met my target sample size. This meant that the opportunity for initial consultation of the interview schedule with participants was missed. However, this was discussed at length with the project supervisors and participants were asked for feedback regarding the interview along the way, to ensure clarity and relevance of the questions asked. Participants provided positive feedback verbally following interviews but very few replied to email requests for more formal and specific feedback. This was not surprising given the busy nature of the working day for these staff members but may have meant that opportunities for constructive feedback were missed. In hindsight, it may have been more productive to provide a short feedback questionnaire following interviews and asked participants to leave them with management in a sealed envelope for me to collect at a later date. This would ensure anonymity and reduce bias.

One area of recruitment that was particularly important to pay attention to was informed consent and participant choice. The recruitment process involved home managers identifying staff members for recruitment and it was not always clear whether the initial agreement to participate came from the manager or the staff member themselves. Therefore, it was important to emphasise to them that it was entirely their choice. This was discussed in private, away from the manager, in order to minimise the influence they may have had on the participant’s decision to participate.

This project privileged staff perspectives and a complimentary study could have included voices of service users, in order to gain an understanding of their experience of PBS being implemented. One area I am particularly pleased with in this project is the consultation with staff members and a community team. I feel that this strengthened the conclusions of this project by ensuring that the findings were relevant, coherent and relatable to the people who use and implement PBS in their everyday practice.

There is considerable evidence that participants of scientific studies experience apprehension about their performance as a participant and how it will be evaluated (Weber & Cook, 1972). Furthermore, given that some participants will have had experience of working with psychologists to develop and implement PBS plans, it may have been that they made assumptions regarding my views and beliefs about PBS. Had participants assumed me to have positive views of the approach, this may have influenced how able they felt to speak negatively, or report more controversial views, of PBS. It was therefore important to ensure my viewpoints of PBS did not come across as much as possible during the interview process. I also emphasised that the purpose of the interview was to explore their experience, positive and negative. It is hoped that this was explicit enough to reduce any apprehension participants had about the interview, and allowed them to speak openly and honestly about their experience.

### Integration

The systematic review and empirical project informed each other throughout the research process. The systematic review looked at reviewing the effectiveness of PBS with adults with ID and challenging behaviour, whilst the empirical project looked at staff experiences of implementing PBS with this population. Had the systematic review not shown PBS to be an effective framework, the empirical project may not have been so relevant and necessary to the field.

These pieces of work share similarities in the populations and demographics of the individuals with ID. Participants in the systematic review aged between 18-86 years old and had a range of abilities, whilst the empirical project involved staff working with individuals with ID aged between 25-70 years old, also with a range of abilities. Both pieces of work contained male and female individuals with ID. All studies in the systematic review were undertaken in high income, Western societies, as were the services where recruitment took place for the empirical project. However, recruitment in the empirical project was less broad, as all three services were recruited from a single county in the south of England. Given the similarities it felt appropriate to synthesise the findings of both pieces.

As both pieces investigated PBS, it allowed me to develop a thorough understanding of the framework and associated strengths and issues. However, this also meant that at times there was considerable overlap between the two pieces and I was conscious of not repeating information between sections of this report. To overcome this, it was important to hold in mind the different objectives of each section in order to ensure only information relevant to these were included.

The findings of both pieces also held some similarities. Unsurprisingly, both pieces identified themes around implementation of PBS. Of the studies in the systematic review that reported intervention fidelity, most of them were poor or substandard, which further emphasises the need for studies such as the empirical project. Despite this, all but one study in the systematic review found PBS to be effective, which is in line with the participants’ views and experiences in the empirical paper, who spoke about PBS being the way forward and a better way of working with adults with ID. Social validity was only measured by one study in the systematic review. The positive views and value placed on PBS by participants in the empirical project would suggest that social validity was high for these services, although further formal investigation of this would lead to firmer conclusions in this matter. Furthermore, participants’ experiences of PBS being a better way of working was linked to more than just behavioural outcomes, the main effective finding in the systematic review. The review’s findings of quality of life showed varied results, with some studies finding an improvement whilst others not. Participants in the empirical study spoke globally about PBS being a better way of working and gave examples of changes to practice, including increase in service user choice and opportunity, improved communication and a holistic view of the individuals they were working with. This provides greater weight to the hypothesis that it is the quality of life measures used within the review studies that do not capture the nuances and complexities of this concept, rather than PBS not being effective in this domain.

Similarities in the themes of training were also noted. Three studies in the systematic review looked at the impact of training staff in using PBS. Participants in the empirical project spoke highly of the training they received, valued its impact and were keen for more training in PBS. These ideas were linked to the theoretical code of being right for the job, as staff were required to have a good understanding of the principles of PBS in order to apply them, a concept which is well recorded in the literature (Dench, 2005; McDonald & McGill, 2013).

From my experience and clinical practice, I was not surprised that intervention fidelity was considered poor overall in the systematic review or by the challenges described by participants in the empirical project. However, I was struck by the understanding of PBS principles and the positive shift in views that direct care staff had for the individuals they support, including the view that PBS is a better way of working. I felt that this viewpoint of PBS was a reflection of their understanding of the principles and evidence of their application of the framework, as their practice may not have shifted towards this without having effectively used PBS and experienced its benefits. This is demonstrated in the reinforcing loop highlighted in the Grounded Theory model in the empirical project. Given that it has been a long time since I have worked in a direct care role, it was positive to see this shift towards the framework, which appears to have happened over time, again in line with the theme of taking time identified in the empirical project.

Finally, it was interesting and helpful to hear about the staff’s experiences of working with different disciplines, such as psychologists and outside agencies. Themes which arose included needing to be involved in plan development, needing to feel their input is valued and wanting clarity over ownership of PBS plans. This insight is important for my own clinical practice and is something I hope to share with other clinicians and services working in social care settings for adults with ID. Ideas for how to go about this are outlined below.

### Impact

The findings of this project have the potential for wide reaching impact. The systematic review was the first of its kind to explore the evidence base for the effectiveness of PBS specifically with adults with ID, whilst only one previous study set out to explore the processes involved with implementing PBS with this population (Woolls et al., 2015). Overall, both pieces of work are in line with previous research relating to the effectiveness of PBS and implementation processes, such as needing adequate knowledge and understanding of an approach to implement it (Denne et al., 2015; Fixsen et al., 2013), benefitting from support from external agencies (Fixsen et al., 2005) and needing a sense of job satisfaction and feedback to reinforce staff’s practice (Fixsen et al., 2005). However, many of these findings have been identified in general health care settings or those implementing PBS with children. This study was amongst the first to look specifically at the processes involved when implementing PBS with adults with ID. Therefore, novel findings were also identified and include needing to involve and value staff input when developing PBS plans, needing to experience PBS in action as well as understanding the theory and principles, and the value of explicitly naming PBS as a mandatory approach in the workplace.

Implications of the findings of these projects have been discussed throughout. Future research identified by the systematic review include improving methodological quality of research in this area, development of valid and reliable measures of quality of life for this population and monitoring and reporting of intervention fidelity. Despite the limitations of existing research, the findings of the systematic review support the recommendation for the use of PBS with adults with ID and challenging behaviour. Given that this is the first review of the literature specific to this population, this is an important and valued finding. A review of the literature in the future would allow for evaluation of the impact this project has had on the evidence base.

Along with the weight that the systemic review adds to the recommendation of the use of PBS, it is hoped that the empirical project is encouraging to staff, services and policy makers that PBS can be implemented successfully, leading to overall improvement in the staff’s experience of their workplace, and specifically PBS, and enhancement of the service user’s quality of life. This may be particularly the case for the participants of this project, as they are likely to be reassured that they have a good understanding of the approach and appear to be ‘right for the job’.

The findings of the empirical project will be translated into a lay summary which will include recommendations for staff and services to take on board, in order to support the implementation and maintenance of PBS, and it is hoped that this study will influence the development of services which are designed to better meet the needs of the individuals that require them. For example, services could tailor their recruitment in order to ensure that the theme of ‘being right for the job’ is considered during this process. This may include checking individuals’ values are in line with PBS principles, considering their communication and reflection skills and their ability to work as a team. Furthermore, training should be utilised to further enhance these areas whilst also developing individuals’ understanding of PBS, in order to better support them to implement it in practice. Training should also be provided for management and senior staff of these services, in order to ensure that supportive work cultures are being provided to staff. Many themes identified in this project are in line with those of practice leadership and it may be that training specifically in this would benefit services.

Furthermore, the findings provide valuable insights for clinicians and community teams working with services that support this population. For example, it is important for those supporting staff teams to implement PBS to know that they need to involve the teams in the development of plans and to value their input. It was also highlighted that staff teams need more explicit understanding of who is responsible for reviewing and updating plans, in order to keep them up to date and relevant for the service user, and hence encouraging their use.

As PBS is an evidence based, best practice approach, it should be the case that it is already being used in practice. Given this, it seems that the recommendations of this project, which give suggestions for how to implement it, are feasible as services should be set up to provide the intervention in the first instance. Furthermore, the approach is considered cost effective (LaVigna & Willis, 2012) and previous research has suggested that lack of financial resources is not an adequate reason for not implementing this approach, as not only does it offer an effective intervention, it has been found to be less costly than alternative approaches (McClean et al., 2007).

Research into the underutilisation of PBS in practice is somewhat out dated and it would be interesting for this to be reviewed following disseminations of this project’s findings. This would provide an idea of how well the recommendations from this project have been disseminated and taken on board, and allow for further planning to support services to implement the approach.

### Dissemination

In order to maximise the impact of this study, findings and conclusions need to be disseminated to the appropriate sources in appropriate formats. Feedback will be provided to the services where recruitment took place. I have offered to attend the services to present the findings to the teams. I will also provide a written lay summary of the findings, including the Grounded Theory model itself. This will allow staff who cannot attend the presentation, and new staff entering the service post-presentation, to be informed of the findings. It also provides the service with something to refer back to over time.

The outcomes of this project will also be disseminated to the clinicians from the community intellectual disabilities team that provided consultation on the developing model and analyse. As these individuals have a knowledge and understanding of research methods and academic journals, the empirical project will be forwarded to them in the finalised format. The study will also be forwarded to other community teams that the researcher and project supervisors have links with, in order to ensure the findings are disseminated as far as possible. In the same vein, the abstracts of both pieces of work will be submitted for publication in the BPS Division of Clinical Psychology Faculty for People with ID bulletin. This means the projects will be shared with over 400 members of the Faculty.

I plan to submit both the systematic review and empirical project for publication within relevant journals. In order to ensure the information is disseminated to the most relevant and appropriate audiences, it is important to consider the journal’s topic of interest and the research designs they are likely to accept for publication. The Journal of Positive Behaviour Interventions aims to expand the knowledge and practice of effective behavioural support for adults in community settings, amongst other populations, and they welcome empirical and qualitative research, and literature reviews. This closely matches the topics and designs of both the systematic review and empirical article and makes this journal a serious consideration for publication of the current work. Furthermore, the impact factor is amongst the highest for journals specifically focusing on individuals with ID. The empirical project has been accepted for poster presentation at the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) conference in August 2019.

Finally, I hope to share the findings of this project with commissioners and policy makers for social care services for adults with ID and plan to do so through discussions with both the research and field supervisors on this project. I feel strongly that findings of this project should be shared with the decision makers at an organisational level. I hope that the positive findings will be reassuring and encouraging to them and show that implementation of an evidence based framework such as PBS can be successfully implemented in these services. I hope they would also provide evidence of service needs and ways of meeting these, in order to best promote the wellbeing of the people that they aim to serve. Given the workload and time pressures that people working at these levels experience, sending an extended executive summary to them, which includes the Grounded Theory model and a narrative description of the findings, would be the most appropriate and effective way of sharing this information with this audience.

# References

Allen, D. (1999). Mediator analysis: An overview of recent research on carers supporting people with intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research, 43*(4), 325-339. https://doi.org/10.1046/j.13652788.1999.00209.x

Allen, D., James, W., Evans, J., Hawkins, S., & Jenkins, R. (2005). Positive Behavioural Support: Definition, current status and future directions. *Learning Disability Review, 10*(2), 4-11.

Allen, D., Jones, E., & Nethell, G. (2018). ‘Clinical outcomes of staff training in positive behavioural support to reduce challenging behaviour in adults with intellectual disability: Further thoughts on intervention, implementation and interpretation’. *International Journal of Positive Behavioural Support*, *8*(1), 4-11.

Allen, D., McGill, P., Hastings, R. P., Toogood, S., Baker, P., Gore, N. J., & Hughes, J. C. (2013). Implementing positive behavioural support: changing social and organisational contexts. *International Journal of Positive Behavioural Support*, *3*(2), 32–41.

Aman, M. G., Singh, N. N., Stewart, A. W. & Field, C. J. (1985). The Aberrant Behavior Checklist: A behavior rating scale for the assessment of treatment effects. *American Journal of Mental Deficiency, (89)*5, 485-491.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders*(5th ed.). Arlington, VA: Author.

Baker, P. (2000). Measurement of community participation and use of leisure by service users with intellectual disabilities: The Guernsey Community Participant and Leisure Assessment (GCPLA). *Journal of Applied Research in Intellectual Disabilities, 13,* 169-195.

Baker, P. & Shepard, J. (2005). The rebranding of behavioural approaches for people with learning disabilities and challenging behaviour. *Learning Disability Review*, *10*(20), 12-15.

Belcher, T. L. (1995). Behavioral treatment vs behavioral control: A case study. *Journal of Developmental and Physical Disabilities*, *7*(3), 235–241. <https://doi.org/10.1007/BF02585428>

Bird, F. L., & Luiselli, J. K. (2000). Positive behavioral support of adults with developmental disabilities: Assessment of long-term adjustment and habilitation following restrictive treatment histories. *Journal of Behavior Therapy and Experimental Psychiatry*, *31*(1), 5–19. <https://doi.org/10.1016/S0005-7916(00)00004-5>

Bird, F. L., Sperry, J. M., & Carreiro, H. L. (1998). Community Habilitation and Integration of Adults with Psychiatric Disorders and Mental Retardation: Development of a Clinically Responsive Environment. *Journal of Developmental and Physical Disabilities*, *10*(4), 331–348. <https://doi.org/10.1023/A:1021802504754>

Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, *13*(1), 68–75. https://doi.org/10.1177/1744987107081254

British Psychological Society & Royal College of Psychiatrists, (2016). *Challenging behaviour: a unified approach – update.* Retrieved from <https://www.rcpsych.ac.uk/pdf/FR_ID_08.pdf>

Campbell, M. (2010) Workforce development and challenging behaviour: Training staff to treat, to manage or to cope? *Journal of Intellectual Disabilities*, *14*(3), 185-196.

Carr, E.G., Horner, R.H., Turnbull, A.P., Marquis, J., Magito-McLaughlin, D., McAtee, M.L., ... Doolabh, A. (1999), *Positive Behaviour Support for People with Developmental Disabilities: A Research Synthesis*. AAMR: Washington, DC.

Carson, G., Clare, I. C. H., & Murphy, G. H. (1998). Assessment and treatment of self-injury with a man with a profound learning disability. *British Journal of Learning Disabilities*, *26*(2), 51–57. <https://doi.org/10.1111/j.1468-3156.1998.tb00048>.

Chapman, M. (Director). (May, 2011). Undercover care: The abuse exposed. [Television series episode] In M. Chapman (Producer), *Panorama*. London: BBC.

Charmaz, K. (2008). Constructionism and the Ground Theory. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of Constructionist Research* (pp. 397-412). New York: The Guildford Press.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). California: Sage Publications Ltd.

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24*, 385 – 396.

Dench, C. (2005). A model for training staff in Positive Behaviour Support. *Learning Disability Review, 10*, 24-30.

Denne, L., Jones, E., Lowe, K., Brown, F. J., & Hughes, J. C. (2015). Putting positive behavioural support into practice : the challenges of workforce training and development. *International Journal of Positive Behavioural Support, 5*(2), 43-54.

Denne, L. D., Noone, S. J., Gore, N. J., Toogood, S., Hughes, J. C., Hastings, R. P., … McGill, P. (2013). Developing a core competencies framework for positive behavioural support: issues and recommendations. *International Journal of Positive Behavioural Support*, *3*(2), 24–31. Retrieved from <http://www.ingentaconnect.com/content/bild/ijpbs/2013/00000003/00000002/art00004>

Denscombe, M. (2013). *The Good Research Guide,* Berkshire: Open University Press.

Department for Work and Pensions & Department of Health and Social Care. (2016). *Improving Lives: The Work, Health and Disability Green Paper*. Retrieved from https://consultations.dh.gov.uk/workandhealth/consult/

Department of Health (2007). *Services for people with learning disabilities and challenging behaviour or mental health needs.* Revised edition (Chairman: Prof J.L. Mansell). London: Department of Health.

Dey, I. (1999). *Grounding grounded theory. Guidelines for qualitative research*. London: Academic Press.

Dunlap, G., & Carr, E. G. (2007). Positive behaviour support and developmental disabilities: A summary and analysis of research. In S. L. Odom, R. H. Horner, M. Snell & J. Blacher (Eds.), *Handbook of developmental disabilities* (pp. 469–482). New York: Guilford.

Dunlap, G., Heineman, M., Knoster, T., Fox, L., Anderson, J. L., & Albin, R. W. (2000). Essential elements of in-service training in positive behavior support. *Journal of Positive Behavior Intervention, 2*(1), 22–32.

Effective Public Health Practice Project. (1998). *Quality Assessment Tool For Quantitative Studies*. Hamilton, ON: Effective Public Health Practice Project. Retrieved from: <https://merst.ca/ephpp/>

Egger, M., & Smith, G. D. (1998). Bias in location and selection of studies. *British Medical Journal (Clinical Research Ed.)*, *316*(7124), 61–66. Retrieved from [www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC2665334](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC2665334)

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*(3), 215-229.

Emerson, E., & Einfield, S. (2012). *Challenging behaviour: Analysis & intervention in people with severe learning disabilities.* Cambridge: Cambridge University Press.

Emerson, E., & Emerson, C. (1987). Barriers to the effective implementation of habiliative behavioural programmes in an institutional setting. *Mental Retardation, 25*(2), 101-106.

Emerson, E., McGill, P. & Mansell, J. (Eds.). (1994). *Severe Learning Disabilities and Challenging Behaviours.* London: Chapman and Hall.

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., & Hillery, J. (2000). Treatment and Management of Challenging Behaviour in Residential Settings. *Journal of Applied Research in Intellectual Disabilities, 13,* 197–215.

Fallowfield, L. (1990). *The Quality of Life. The Missing Measurement in Health Care*. Souvenir Press, London.

Fixsen, D., Blase, K., Metz, A., & Van Dyke, M. (2013). Statewide Implementation of Evidence-Based Programs. *Exceptional Children, 79*(3), 213–230. https://doi.org/10.1177/001440291307900206

Fixsen, D., Naoom, S. F., Blase, K. A., Friedman, R. M., & Wallace, F. (2005). *Implementation Research: A Synthesis of the Literature*. Tampa, FL: University of South Florida.

Foster, S. L., & Mash, E. J. (1999). Assessing social validity in clinical treatment research: Issues and procedures. *Journal of Consulting and Clinical Psychologist, 67*(3), 308–319.

Gillberg, C. & Soderstrom, H. (2003). Learning Disability. *The Lancet, 362,* 811-821.

Goh, A. E., & Bambara, L. M. (2012). Individualized Positive Behavior Support in School Settings: A Meta-Analysis. *Remedial and Special Education*, *33*(5), 271–286. <https://doi.org/10.1177/0741932510383990>

Gore, N. J., McGill, P., Toogood, S., Allen, D., Hughes, J. C., Baker, P., … Denne, L. D. (2013). Definition and scope for positive behavioural support. International Journal of Positive Behavioural Support. *International Journal of Positive Behavioural Support*, *3*(2), 14–23.

Grol, R. & Wensing, M. (2004). What Drives Change? Barriers to and Incentives for Achieving Evidence-Based Practice. *The Medical Journal of Australia, 180,* 57-60.

Hallgren, K. A. (2012). Computing Inter-Rater Reliability for Observational Data: An Overview and Tutorial. *Tutorials in Quantitative Methods for Psychology*, *8*(1), 23–34. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/22833776%0Ahttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3402032>

Harris, P. (1993). The Nature and Extent of Aggressive Behaviour amongst People with Learning Difﬁculties (Mental Handicap) in a Single Health District. *Journal of Intellectual Disability Research 37,* 221–242.

Hassiotis, A., Canagasabey, A., Robotham, D., Marston, L., Romeo, R., & King, M. (2011). Applied behaviour analysis and standard treatment in intellectual disability: 2-year outcomes. *British Journal of Psychiatry*, *198*(6), 490–491. <https://doi.org/10.1192/bjp.bp.109.076646>

Hassiotis, A., Poppe, M., Strydom, A., Vickerstaff, V., Hall, I. S., Crabtree, J., ... Crawford, M. (2018a). Clinical outcomes of staff training in positive behaviour support to reduce challenging behaviour in adults with intellectual disability: cluster randomised controlled trial. *British Journal of Psychiatry, 212*(3), 161–8. <https://doi.org/10.1192/bjp.2017.34>

Hassiotis, A., Poppe, M., Strydom, A., Vickerstaff, V., Hall, I., Crabtree, J., ... Crawford, M. (2018b). Positive behaviour support training for staff for treating challenging behaviour in people with intellectual disabilities: a cluster RCT. *Health Technology Assessment, 22*(15), 1-142.

Hassiotis, A., Strydom, A., Crawford, M., Hall, I., Omar, R., Vickerstaff, V., … King, M. (2014). Clinical and cost effectiveness of staff training in Positive Behaviour Support (PBS) for treating challenging behaviour in adults with intellectual disability: A cluster randomised controlled trial. *BMC Psychiatry*, *14*(1), 1–10. <https://doi.org/10.1186/s12888-014-0219-6>

Hastings, R. P. (1997). Measuring staff perceptions of challenging behaviour: The Challenging Behaviour Attributions Scale (CHABA). *Journal of Intellectual Disability Research, 41*, 495–501. https://doi. org/10.1111/j.1365-2788.1997.tb00742.x

Hastings, R. P. (2002). ‘Do challenging behaviors affect staff psychological well-being? Issues of causality and mechanism’. *American Journal on Mental Retardation, 107*, 455–467.

Health Education England. (2017). *Our Values.* Retrieved from <https://www.hee.nhs.uk>

Houchins, D., Jolivette, K., Wessendorf, S., McGlynn, M. & Nelson, M. (2005). Stakeholder’s View of Implementing Positive Behavioural Support in Juvenile Justice Settings. *Education and Treatment of Children, 28*(4), 380-399.

Howitt, D. & Cramer, D. (2011). *Introduction to Research Methods in Psychology* (3rd ed.). Harlow, England: Pearson Education Limited.

Inchley-Mort, S., Rantell, K., Wahlich, C., & Hassiotis, A. (2014). Complex behaviour service: Enhanced model for challenging behaviour. *Advances in Mental Health and Intellectual Disabilities, 8*(4), 219-227. https://doi.org/10.1108/AMHID-08-2013-0056.

Janssen, C. G. C., Schuengel, C., & Stolk, J. (2002). Understanding challenging behaviour in people with severe and profound intellectual disability: A stress-attachment model. *Journal of Intellectual Disability Research*, *46*(6), 445–453. <https://doi.org/10.1046/j.1365-2788.2002.00430.x>

Johnson, L. A. D. (2017). Going to scale: exploring implementation of positive behaviour intervention and supports within and across different types of early childhood programmes. *Early Child Development and Care*, *189*(4), 523–540. <https://doi.org/10.1080/03004430.2017.1331219>

Johnson, M. & May, C. (2015). Promoting professional behaviour change in healthcare: What interventions work, and why? A theory-led overview of systematic reviews. *British Medical Journal, 5,* 1-13.

Kazdin, A. E. (2011). *Single-case research designs: Methods for clinical and applied settings*. New York, NY, US: Oxford University Press.

Kemp, D. C. & Carr, E. G. (1995). Reduction of severe problem behavior in community employment using an hypothesis-driven multicomponent treatment approach. *The Association for Persons with Severe Handicaps, 20*(4), 229-247.

Kincaid, D., Childs, K., Blase, K. & Wallace, F. (2007). Identifying barriers and facilitators in implementing school wide Positive Behaviour Support. *Journal of Positive Behaviour Interventions, 9*(3), 174-184.

Kotter, J. (2012). *Leading Change.* Cambridge: Harvard Business Review Press.

LaLoux, F. (2014). *Reinventing Organisation: A Guide to Creating Organizations Inspired by the Next Stage in Human Consciousness.* Belguim: Nelson Parker.

LaVigna, G. W., & Willis, T. J. (2005). A Positive Behavioural Support model for breaking the barriers to social and community inclusion. *Tizard Learning Disability Review*, *10*(2), 16-23. <https://doi.org/10.1108/13595474200500016>.

LaVigna, G. W. & Willis, T. J. (2012). The Efficacy of Positive Behavioural Support with the most challenging behaviour: The evidence and its implications. *Journal of Intellectual & Developmental Disability, 37*(3), 185-195. <https://doi.org/10.3109/13668250.2012.696597>

LaVigna, G. W., Willis, T. J., & Donnellan, A. M. (1989). The role of positive programming in behavioral treatment. In E. Cipani (Ed.), *The treatment of severe behavior disorders* (pp. 59-83)*.* Washington, DC: American Association on Mental Retardation.

LaVigna, G. W., Willis, T. J., Shaull, J., Abedi, M., & Sweitzet, M. (1994). *The Periodic Service Review: A total quality assurance system for human services and education*. Baltimore: Paul H. Brookes.

Lenz, A. S. (2013). Calculating effect size in single-case research: A comparison of nonoverlap methods. *Measurement and Evaluation in Counseling and Development*, *46*(1), 64–73. <https://doi.org/10.1177/0748175612456401>

Levasseur, M., Desrosiers, J., & Noreau, L. (2004). Is social participation associated with quality of life of older adults with physical disabilities? *Disability and Rehabilitation*, *26*(20), 1206–1213. <https://doi.org/10.1080/09638280412331270371>

Lobo, M. A., Moeyaert, M., Cunha, A. B., & Babik, I. (2017). Single-case design, analysis, and quality assessment for intervention research. *Journal of Neurologic Physical Therapy*, *41*(3), 187–197. <https://doi.org/10.1097/NPT.0000000000000187>

Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K., & James, W. (2007). Challenging behaviours: Prevalence and topographies. *Journal of Intellectual Disability Research*, *51*(8), 625–636. <https://doi.org/10.1111/j.1365-2788.2006.00948.x>

Lowe, K., Jones, E., Horwood, S., Gray, D., James, W., Andrew, J., ... Allen, D. (2010). The evaluation of periodic service review (PSR) as a practice leadership tool in services for people with intellectual disabilities and challenging behaviour. *Tizard Learning Disability Review, 15*(3), 17-28.

Luiselli, J. K., Sperry, J. M., & Connolly, N. M. (2002). Elimination of mechanical restraint, community-based behaviour support, and seven-year maintenance evaluation in the treatment of a woman with mental retardation and multiple psychiatric disorders. *Mental Health Aspects of Developmental Disabilities, 5*(3), 69-77.

MacDonald, A. (2018). A commentary on ‘Clinical outcomes of staff training in positive behavioural support to reduce challenging behaviour’ A commentary on ‘Clinical outcomes of staff training in positive behavioural support to reduce challenging behaviour in adults with intellectual disability: Further thoughts on intervention, implementation and interpretation’. *International Journal of Positive Behaviour Support, 8*(1), 12–21.

MacDonald, A., Hume, L., & McGill, P. (2010). The use of multi-element behaviour support planning with a man with severe learning disabilities and challenging behaviour. *British Journal of Learning Disabilities*, *38*(4), 280–285. <https://doi.org/10.1111/j.1468-3156.2009.00602.x>

MacDonald, A. & McGill, P. (2013). Outcomes of staff training in Positive Behaviour Support: A systematic review. *Journal of Developmental and Physical Disabilities, 25,* 17-33. <https://doi.org/10.1007/s10882-012-9327-8>

MacDonald, A., McGill, P., & Murphy, G. (2018). An evaluation of staff training in positive behavioural support. *Journal of Applied Research in Intellectual Disabilities*, *31*(6), 1046–1061. <https://doi.org/10.1111/jar.12460>

Mansell, J., & Beadle-Brown, J. (2005). *Engagement in meaningful activity and relationships: An observational measure.* Canterbury, UK: Tizard Centre.

Mansell, J., Beadle-Brown, J., Macdonald, S., & Ashman, B. (2003). Resident involvement in activity in small community homes for people with learning disabilities. *Journal of Applied Research in Intellectual Disabilities, 16,* 63–74. https://doi. org/10.1046/j.1468-3148.2003.00146.x

Mansell, J., Elliott, T. E., & Beadle-Brown, J. (2005). *Active support measure (Revised).* Canterbury, UK: Tizard Centre.

Mansell, J., Hughes, H., & McGill, P. (1994). Maintaining local residential placements. In E. Emerson, P. McGill, & J. Mansell (Eds.), *Severe learning disabilities and challenging behaviours: Designing high-quality services* (pp. 261–281). London, UK: Chapman and Hall.

Marquis, J. G., Horner, R. H., Carr, E. G., Turnbull, A. P., Thompson, M., Behrens, G. A., . . . Ryan, K. A. (2000). A meta-analysis of Positive Behaviour Support. In *Contemporary special education research: Syntheses of the knowledge base on critical instructional issues* (137-178). New York: Routlage.

McClean, B., Grey, I. M., McCracken, M. (2007). An evaluation of positive behavioural support for people with very severe challenging behaviours in community-based settings. *Journal of Intellectual Disabilities, 11*(3), 281-301.

McClintock, K., Hall, S. & Oliver, C. (2003). Risk markers associated with challenging behaviours in people with intellectual disabilities: a meta-analytic study. *Journal of Intellectual Disability Research, 47*(6), 405-416.

McGill, P., Bradshaw, J., Smyth, G., Hurman, M. & Roy, A. (2014). [Capable Environments](http://www.kcl.ac.uk/sspp/kpi/scwru/news/2014/newsfolder/McGill-et-al-Capable-environments.pdf). In Banks, R. & Bush, A. (Eds.), *Challenging Behaviour: A Unified Approach (pp. 1-11).* Retrieved from: <https://www.kcl.ac.uk/scwru/mrc/events2014/ldss13jan14>

McGill, P., Vanono, L., Clover, W., Smyth, E., Cooper, V., Hopkins, L., … Deveau, R. (2018). Reducing challenging behaviour of adults with intellectual disabilities in supported accommodation: A cluster randomized controlled trial of setting-wide positive behaviour support. *Research in Developmental Disabilities*, *81,* 143–154. <https://doi.org/10.1016/j.ridd.2018.04.020>

Moss, S., Prosser, H., Costello, H., Simpson, N., Patel, P., Rowe, S., ... Hatton, C. (1998) Reliability and validity of the PASADD Checklist for detecting psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research, 42*(2), 173–83.

NHS England (2017). *Transforming Care, Model Service Specifications: Supporting Implementation of the Service Model.* England: NHS England.

NHS England, Association of Directors of Adult Social Services & Local Government Association. (2015). *Building the Right Support.* Retrieved from:

<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

National Institute for Health and Care Excellence. (2015). *Challenging behaviour and learning disabilities: Prevention and interventions for people with learning disabilities whose behaviour challenges* (NICE Guideline 11). Retrieved from: https://www.nice.org.uk/guidance/ng11

Nihira, K., Leland, H., & Lambert, N. (1993). *AAMR adaptive behaviour scale—residential and community* (2nd ed.). Austin, Texas: Pro-Ed.

Northway, R., & Jenkins, R. (2003). Quality of life as a concept for developing learning disability nursing practice? *Journal of Clinical Nursing, 12,* 57-66.

Odom, S. L., Horner, R. H., Snell, M. E., & Blacher, J. (2007). *Handbook of Developmental Disabilities.* New York: The Guildford Press.

Parker, R. I. & Brossart, D. F. (2003). Evaluating Single-Case Research Data : A Comparison of Seven Statistical Methods. *Behaviour Therapy, 34,* 189–211.

Plomin, J. (Director). (May, 2019). Undercover hospital abuse scandal. [Television series episode] In K. Wightman (Executive Producer), Panorama. London: BBC.

Raczka, R., Theodore, K., & Williams, J. (2018, June). An initial validation of a new quality of life measure for adults with intellectual disability : The Mini-MANS-LD. *Journal of Intellectual Disabilities,* 1-17*.* <https://doi.org/10.1177/1744629518787895>

Roy, A., Matthews, H., Clifford, P., Fowler, V., & Martin, D. M. (2002). Health of the nation outcome scales for people with learning disabilities (HoNOS-LD). *The British Journal of Psychiatry: The Journal of Mental Science, 180*, 61-66. <https://doi.org/10.1192/bjp.180.1.61>.

Royal College of Psychiatrists, British Psychological Society, Royal College of Speech and Language Therapists (2007) *Challenging Behaviour: A Unified Approach* (CR144). Retrieved from <https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr144.pdf?sfvrsn=73e437e8_2>

Schall, C. M. (2010). Positive behavior support : Supporting adults with autism spectrum disorders in the workplace. *Journal of Vocational Rehabilitation,* *32*, 109–115. <https://doi.org/10.3233/JVR-2010-0500>

Schalock, R. L., Keith, K. D., Hoffman, K. & Karan, O. C. (1989). Quality of Life: Its Measurement and Use. *Mental Retardation, 27*, 25–31.

Scruggs, T. E., & Mastropieri, M. A. (1998). Summarizing single-subject research: Issues and applications. *Behavior Modification, 22*(3), 221-242. https://doi.org/10.1177/01454455980223001.

Scruggs, T. E., & Mastropieri, M. A. (2012). PND at 25: Past, Present, and Future Trends in Summarizing Single-Subject Research.  *Remedial and Special Education*, *34*(1), 9–19. <https://doi.org/10.1177/0741932512440730>

Scruggs, T. E., Mastropieri, M. A., & Casto, G. (1987). The quantitative synthesis of single-subject research: Methodology and validation. *Remedial and Special Education, 8*(2), 24-33. https://doi.org/10.1177/074193258700800206.

Shepard, J. (2012). In Celebration: Living a Life through Positive Behaviour Support. *Tizard Learning Disability Review, 17*(2), 69-75.

Sigafoos, J., & Tucker, M. (2006). Brief assessment and treatment of multiple challenging behaviors. *Behavioral Interventions, 15,* 53–70.

Singh, N. N., Lancioni, G. E., Karazsia, B. T., & Myers, R. E. (2016). Caregiver Training in Mindfulness-Based Positive Behavior Supports (MBPBS): Effects on Caregivers and Adults with Intellectual and Developmental Disabilities. *Frontiers in Psychology, 7*(98), 1-11. doi: 10.3389/fpsyg.2016.00098

Singh, N. N., Lancioni, G. E., Medvedev, O. N., Myers, R. E., Chan, J., Mcpherson, C. L., … Kim, E. (2018, January). Comparative Effectiveness of Caregiver Training in Mindfulness-Based Positive Behavior Support (MBPBS) and Positive Behavior Support (PBS) in a Randomized Controlled Trial. *Mindfulness,* 1-13. doi: 10.1007/s12671-018-0895-2

Skelly, A. (2016). Maintaining the Bond: Working with people who are described as showing challenging behaviour using a framework based on attachment theory. In Fletcher, H. K., Flood, A., & Hare, D. J. (Eds.), *Attachment in Intellectual and Developmental Disability: A Clinician’s Guide to Practice and Research* (pp. 104-129). Chichester: John Wiley & Sons Ltd.

Skirrow ,P., & Perry, .E (2009). *The Maslow Assessment of Needs Scale (MAN*S). Liverpool: Mersey Care NHS Trust.

Spencer, L. & Ritchie, J. (2012). In pursuit of quality. In Harper, D. & Thompson, A. R. (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy* (pp. 227-242). Chichester: John Wiley & Sons Ltd.

Stamm, B. H. (2010). *The concise ProQOLmanual* (2nd ed.). Pocatello, ID: ProQOL.org.

Testa, M. A., & Simonson, D. C. (1996). Assessment of Quality-of-Life Outcomes. *The New England Journal of Medicine, 334*(13), 835-840.

Thomas, B., Ciliska, D., Dobbins, M., & Micucci, S. (2004). A process for systematically reviewing the literature: Providing the research evidence for public health nursing interventions. *Worldviews on Evidence‐Based Nursing, 1*(3), 176-184. <https://doi.org/10.1111/j.1524-475X.2004.04006.x>.

Vannest, K. J., & Ninci, J. (2015). Evaluating intervention effects in single-case research designs. *Journal of Counseling & Development, 93*, 403–411. <https://doi.org/10.1002/jcad.12038>

Wardale, S., Davis, F., Vassos, M., Nankervis, K., Wardale, S., Davis, F., … Nankervis, K. (2018). The outcome of a statewide audit of the quality of positive behaviour support plans plans. *Journal of Intellectual & Developmental Disability*, *43*(2), 202–212. <https://doi.org/10.3109/13668250.2016.1254736>

Weber, S. J., & Cook, T. D. (1972). Subject effects in laboratory research: An examination of subject roles, demand characteristics, and valid inference. *Psychological Bulletin, 77*(4), 273-295. <https://doi.org/10.1037/h0032351>

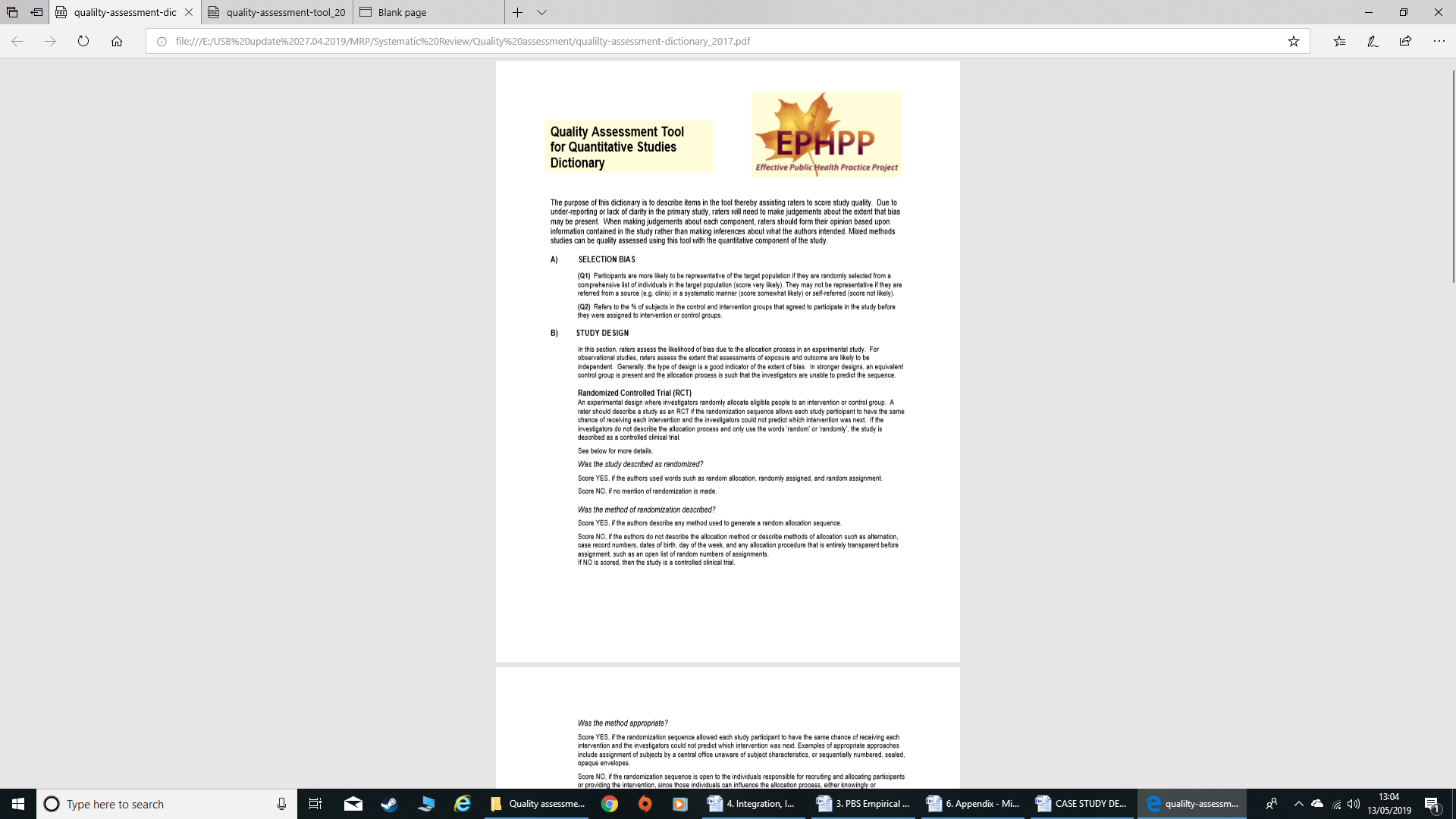
West, E. A. & Patton, H. A. (2010). Positive behaviour support and supported employment for adults with severe disability. *Journal of Intellectual and Developmental Disability, 35*(2), 104-111.

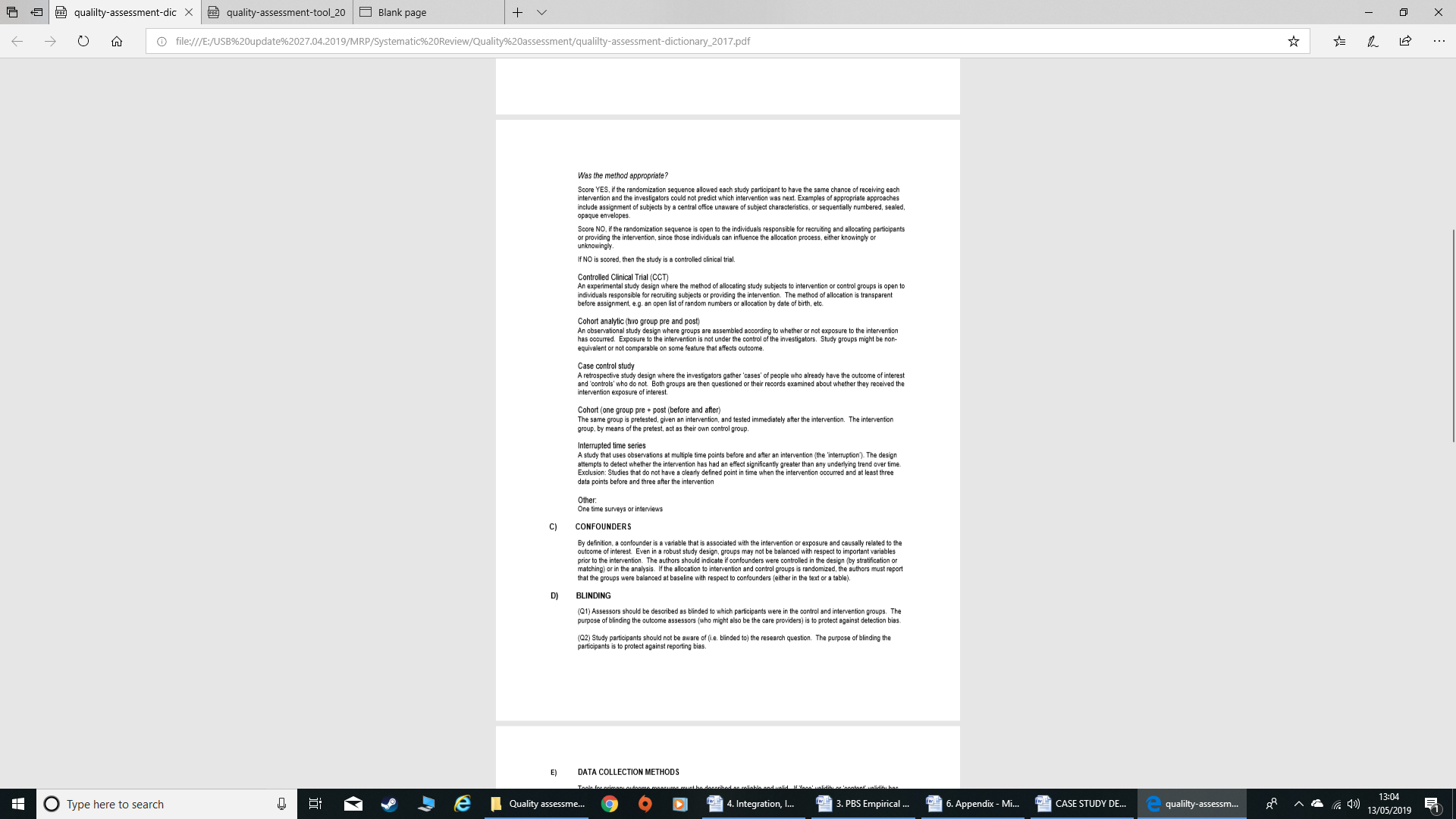
Woolls, S., Allen, D., & Jenkins, R. (2012). Implementing positive behavioural support in practice: The views of mediators and consultants. *International Journal of Positive Behavioural Support, 2*(2), 42-54.

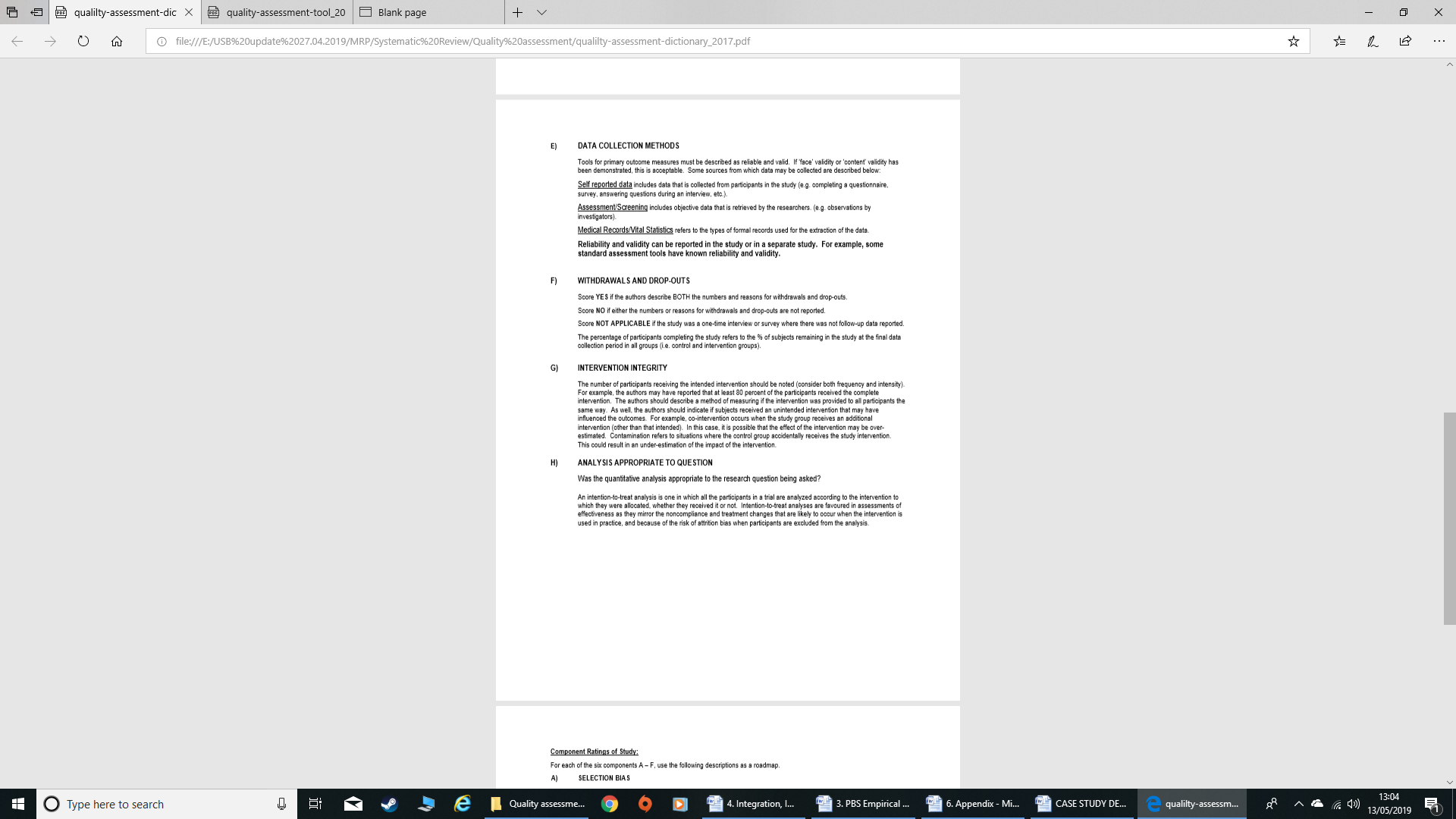
Xenitidis, K., Thornicroft, G., Leese, M., Slade, M., Fotiadou, M., Philp, H., ... Murphy, D. G. M. (2000). Reliability and validity of the CANDID - A needs assessment instrument for adults with learning disabilities and mental health problems. *British Journal of Psychiatry, 176*(May), 473-478. <https://doi.org/10.1192/bjp.176.5.473>

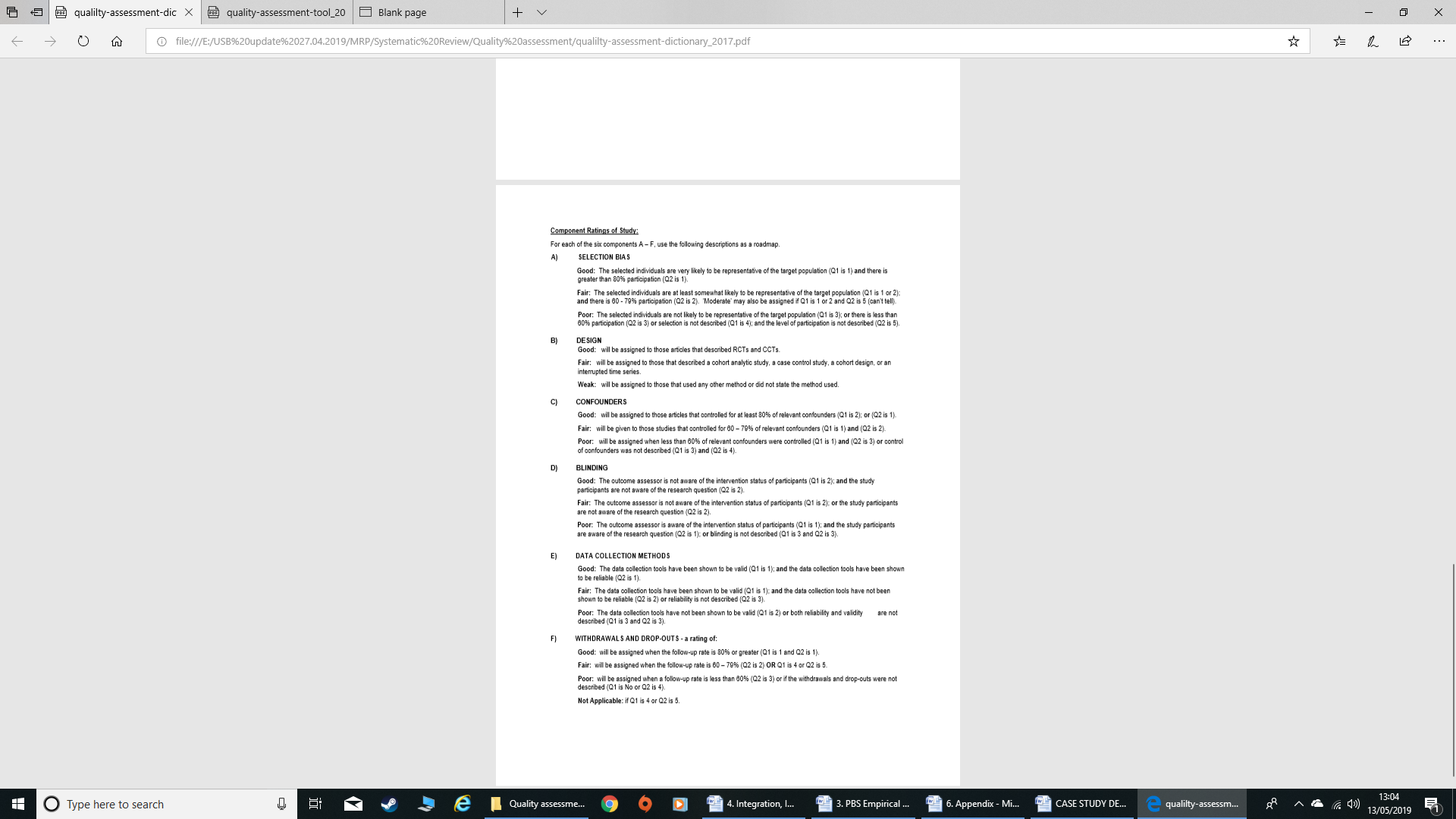
# Appendices

## Appendix 1: Quality Assessment Tool for Quantitative Studies Dictionary

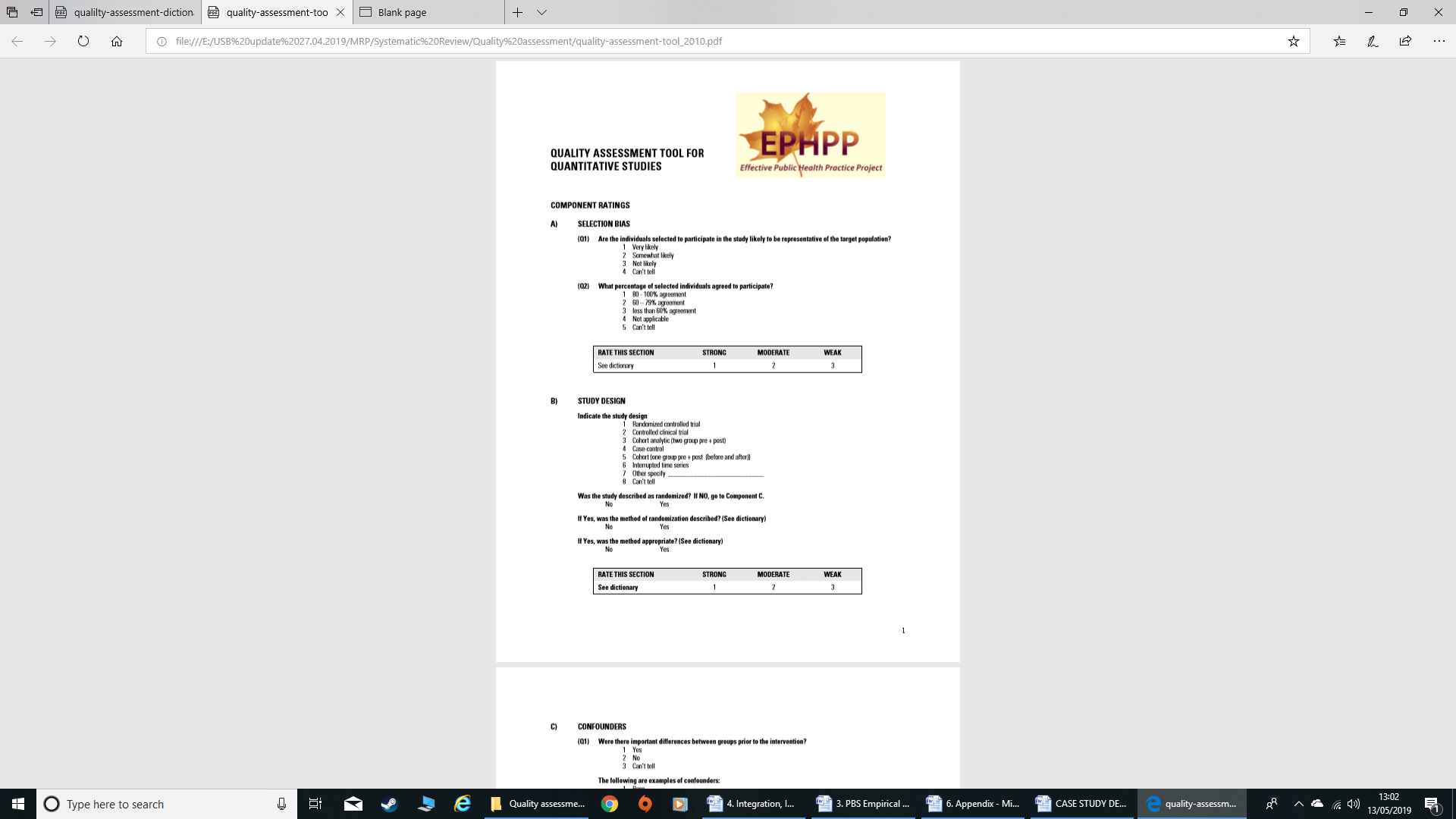
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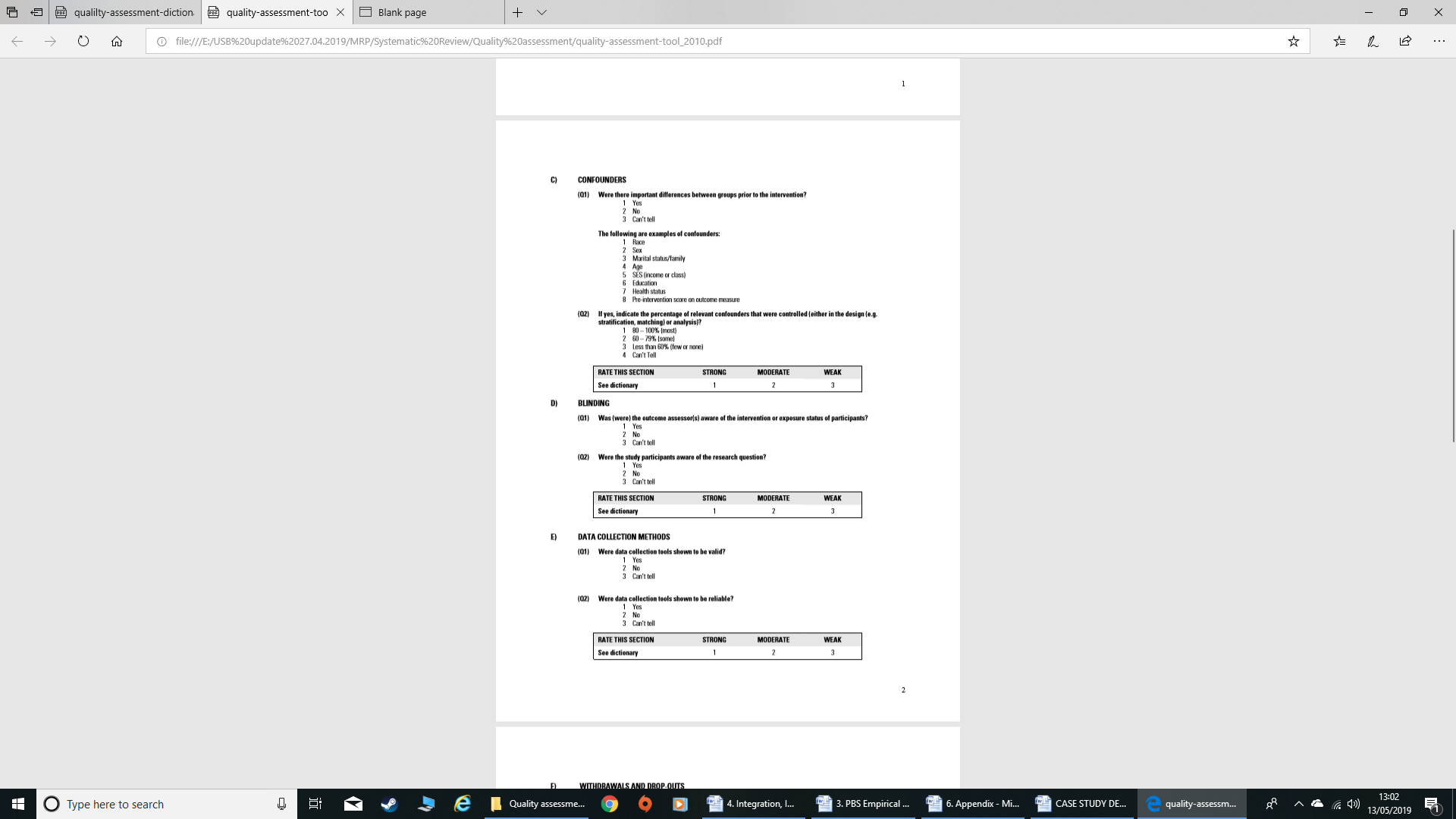
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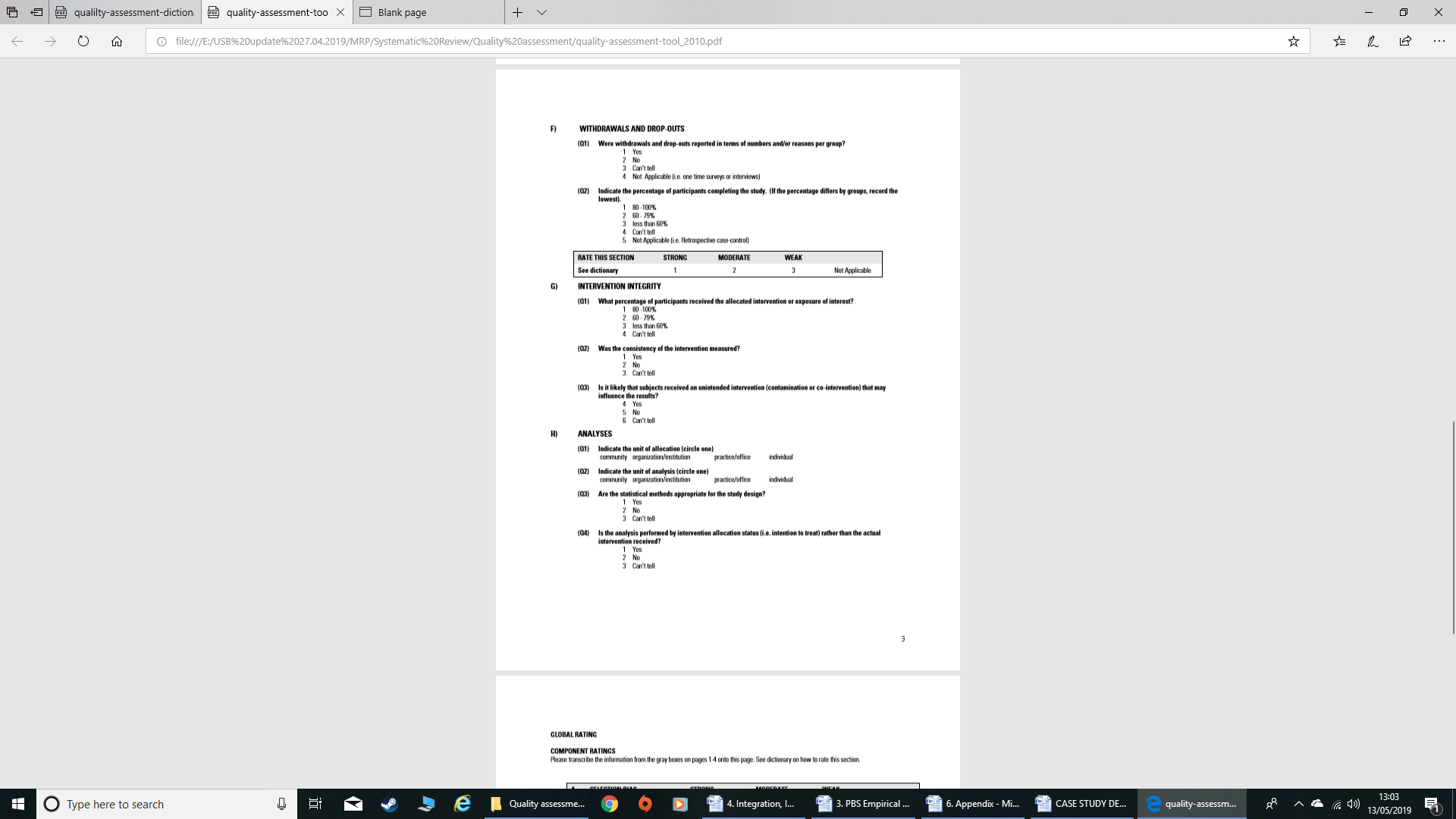
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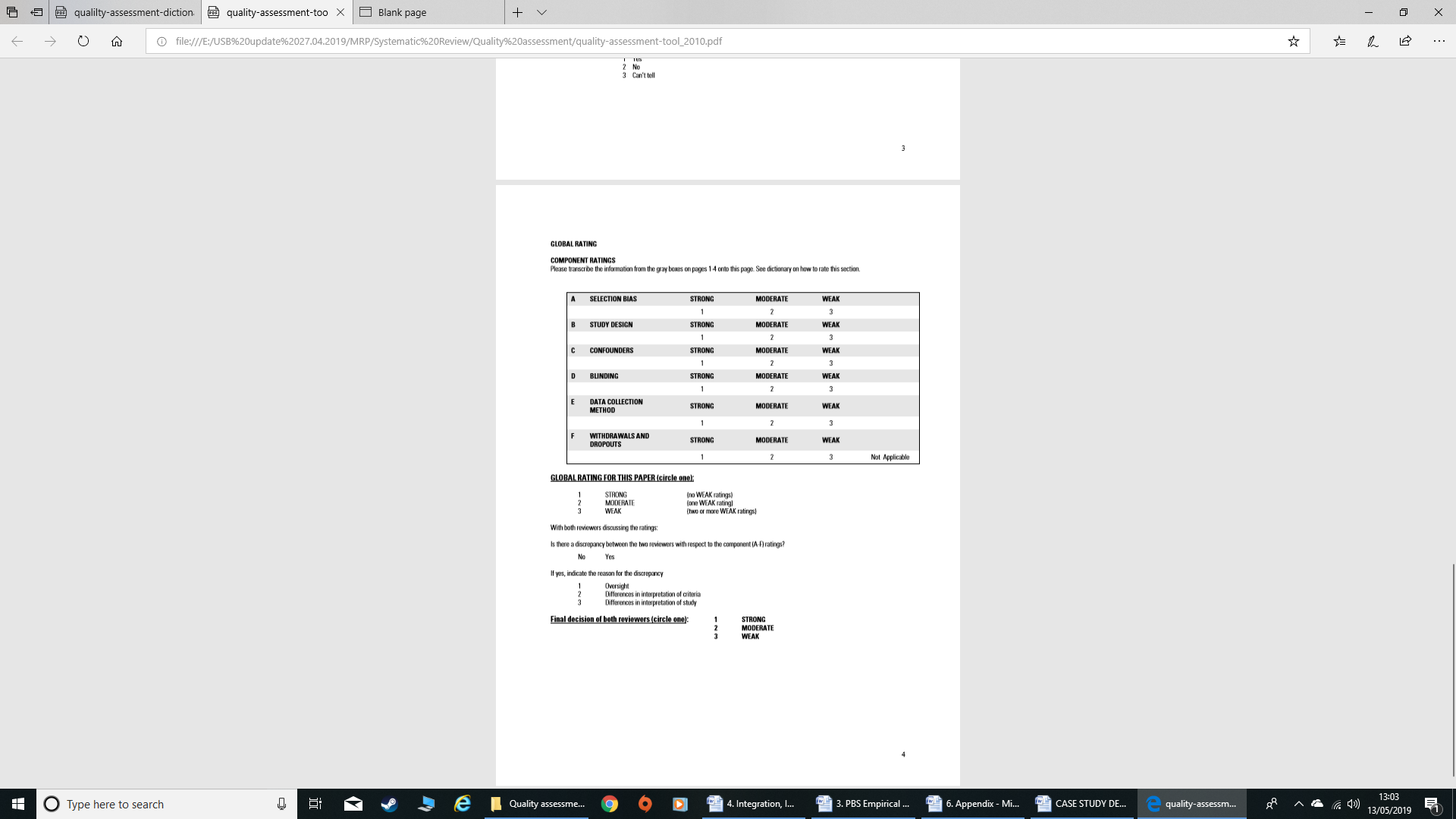
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## Appendix 2: Quality Assessment Tool for Quantitative Studies

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## Appendix 3: Single Case Design Supplement to Quality Assessment Tool for Quantitative Studies

**Supplement for ‘QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES’ to be used with articles with case study design**

B) STUDY DESIGN

Single-case studies which utilised an experimental design should be considered to have **moderate** quality.

C) CONFOUNDERS

Were confounding factors considered during the planning of the intervention? I.e. does author make it clear they ensured no other changes where occurring during period of implementation of intervention?

The following are examples of confounders: Significant life events, changes in staffing, significant changes to the environment, other changes to individual’s circumstances.

Articles identifying that they considered confounding factors and none were identified should be rated as **strong** and those that did not consider or identify confounders rate as **weak**. If there are significant changes or confounding factors identified, rate this section as **moderate**.

D) BLINDING

Outcome measure ratings completed by the lead research or an interventionist (staff implementing intervention directly with the service user) who is aware of the research question should be scored as **weak** on this item. Score as **moderate** if rater is impartial (i.e. not involved in the research) OR blind to the research question. Score as **strong** if rater is impartial AND blind to the research question.

F) FOLLOW UP/MAINTENANCE

For withdrawals and drop-outs, this should be scored as **weak** if there was no maintenance/follow-up period for single case studies. Follow ups of more than 2 years should be rated as **strong** and less than 2 years as **moderate.**

G) OUTCOME MEASURE RELIABILITY

Score as **strong** where rater is trained in measuring the outcome AND inter rater reliability is at least 80%. Score as **moderate** where rater is trained in measuring the outcome OR inter rater reliability is at least 80%. Score as **weak** if not considered or reported.

*Use your own judgement where authors are not clear. If authors have considered and controlled for these areas, it is more likely that they will report them than not, therefore items should be marked down for not including them in the write up.*

## Appendix 4: Participant Information Sheet

**Department of Psychology, Royal Holloway, University of London**

**Surrey and Borders NHS Foundation Trust**

IRAS ID: 238871

**Participant Information Sheet**

**An investigation of Positive Behaviour Support in Social Care Settings**

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team members will go through this information sheet with you and answer any questions that you may have. We think this should take about 10 minutes.

Talk to others about the study if you wish.

Ask us if anything is unclear.

**What is the project about?**

This project is about the use of Positive Behaviour Support (PBS) in social care settings for adults with Learning Disabilities. We are interested in how services put PBS into practice, what helps staff working in these services use PBS and what challenges they may experience. We would like to talk to people who work in these services. The major goal of this study is to help services to better understand the barriers experienced when putting PBS into practice and what can be done to support staff through this process. We hope to use the information learnt from this project to provide guidance and recommendations for the use of PBS to similar services.

*If you’re interested in taking part, please read the extra information below before you decide.*

**Why have I been invited?**

You have been invited to take part because you work in a social care setting with adults with Learning Disabilities, ran by Surrey and Borders NHS Foundation Trust.

We hope to speak to 12-15 people that work in these types of services.

**Do I have to take part?**

**It is up to you** to decide whether to join the study. If you like, you can talk to others about the study before you decide. If you agree to take part, we will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. Your decision to take part has no impact on your employment.

**What will happen if I take part?**

If you decide to take part, a researcher will come to meet with you at your place of work. We will try and arrange a time which is most convenient to you and the service.

We will go through this information with you, and if you decide you would still like to participate we will ask you to sign a consent form.

You will have an **interview, which will last for around an hour**. You can choose how much to say. You can choose not to answer any specific question without giving a reason. We will use a **tape recorder** to record what you tell us. This is so the interview can be transcribed accurately for analysis. Once it has been transcribed, the audio file will be destroyed. You can also decide to stop the interview at any point if you no longer wish to participate.

We will ask you some questions about the use of PBS in your service and how this was put into practice. We will ask you how you find the use of PBS in your service, and if anything made it easier or more difficult to put into practice. We will ask you whether you experienced any challenges with this and if and how these were managed.

After we have talked to 12-15 staff members, we will let the service know what we found. When the project is complete, we hope to present the findings of the project to the services involved. We will also provide a written summary to the services and participants that take part.

**Will my taking part in this study remain confidential?**

Yes. Everything that you told us in the interview would remain confidential. The exception to this rule would be if you told us something that indicated that you or someone else was at risk of serious harm. In that case, we may need to involve other professionals. We would try to discuss this with you before doing so. We will use direct quotes in the write up of the project, but we will not use your name or any other personally identifiable information.

The interview will be recorded onto a digital recording device. After the interview is completed it will be transcribed and stored in a secure file on a computer and the audio file will be destroyed.

The transcribed interview will not have your name or any other personally identifiable information on it.

**What are the possible disadvantages and risks of taking part?**

We do not anticipate that there are any risks involved in taking part in the study. The study will take up around an hour of your working day.

We do not anticipate that we will discuss sensitive or personal topics during the interviews, however if you have experienced difficulties or challenges at work that upset you during the interview, we would stop the interview and ask you how you would best like to be supported. You would have the option of discontinuing the interview at any time.

**What are the possible benefits of taking part?**

We cannot promise that there will be any benefits to you from taking part. However some people find that talking about their experiences in a non-judgemental environment can be a positive experience. The interview would provide an opportunity to be heard, in a way that is important and useful.

The interview would provide you with an opportunity to explore and discuss challenges experienced at work. It is an opportunity to provide feedback on processes undertaken within the service where you work and to contribute towards research which may influence future services for adults with Learning Disabilities.

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

If you decide that you no longer wish to continue with the study, you can decide to stop at any point, without giving a reason. Any information that has already been recorded would be destroyed and disposed of.

**What if there is a problem?**

If you have a concern about this study, you should speak to the researcher who will do their best to answer your questions. You can also speak to the research supervisors, Dr Inês Mendes and Dr Kate Theodore. They are based at Royal Holloway, University of London. All contact details are at the end of this document.

If you remain unhappy and wish to complain formally, you can do this by contacting Gary Brown (research sponsor on behalf of Royal Holloway, University of London) He can be contacted on 01784 414330 or Gary.Brown@rhul.ac.uk

**How will my information be kept confidential?**

Royal Holloway, University of London, is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Royal Holloway, University of London, will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Royal Holloway, University of London, will keep your name and contact details confidential and will not pass this information to anyone else. Royal Holloway, University of London, will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded and to oversee the quality of the study. Certain individuals from Royal Holloway, University of London, and regulatory organisations may look at your research records to check the accuracy of the research study. They will only receive information without any identifying information. They will not be able to identify you and will not be able to find out your name or contact details.

Your information will be stored securely. Your interview answers will be stored without your name on them. Audio recordings will be deleted as soon as the interview has been typed up. Your personal details, such as name and address, will be destroyed once we have met with you to feed back the results. We won’t use these for future studies. Only the researchers and people who inspect research will have access to your data.

**Who is organising and funding the research?**

The research is being funded by Royal Holloway University of London, where the chief investigator of the project is studying a Doctorate in Clinical Psychology. This research study is part of their course requirements.

**What will happen to the results?**

When the study is completed, the results will be written up into a report. We may use direct quotes from the interview in this report. We would not use your name or any other personally identifiable information in the report.

The report will be submitted to academic journals for publication so that other professionals could access our findings. We would also like to share the results of the study with all those who participated in it. A copy of the report would be made available to you if you wished to see it.

Further Information and Contact Details:

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*If you decide to take part, you will be given a copy of this information sheet and a signed consent form to keep.*

Thank you for your time

## Appendix 5: Participant Demographic Questionnaire

**Department of Psychology, Royal Holloway, University of London**

**Surrey and Borders NHS Foundation Trust**

IRAS ID: 238871

Participant Identification Number for this trial:

**An investigation of Positive Behaviour Support in Social Care Settings**

**Demographic Questionnaire**

The following questions will help us have a better understanding of the individuals that have participated in this project. This information will be kept confidential and will not be stored with your name.

|  |  |  |  |
| --- | --- | --- | --- |
| Age: |  | | |
| Gender: |  | | |
| Job Role: |  | | |
| When did you start this role? | |  | |
| If you have worked in the service in different roles, please specify what these were and when you started them? (Leave blank if in the same role as when you started with the service) | | | |
| Job Role: | | | Start Date: |
| Job Role: | | | Start Date: |
| How long have you worked in care services for adults with Learning Disabilities? | | | |
| What training have you had in managing and supporting individuals with Challenging Behaviour? | | | |
| What training have you had in Positive Behaviour Support? | | | |
| How long have you been using PBS in your daily practice? | | | |

*If you have any questions about this questionnaire, please speak to the researcher.*

## Appendix 6: Service Questionnaire

**Department of Psychology, Royal Holloway, University of London**

**Surrey and Borders NHS Foundation Trust**

IRAS ID: 238871

Service Identification Number for this trial:

**An investigation of Positive Behaviour Support in Social Care Settings**

**Service Information Questionnaire**

The following questions will help us have a better understanding of the services where participants of this project work and the service users they are supporting. This information will be kept confidential and will not be stored with the service name.

|  |  |
| --- | --- |
| When was PBS implemented in the service? |  |
| Over what time period was PBS implemented in the service? |  |
| How many service users reside in the service? | Males:  Females:  Total: |
| What is the age range of service users in the service? |  |
| What are the ethnic and religious backgrounds of the service users? |  |
| Please list all diagnoses given to service users:  *(for example, Learning Disabilitiy, Autism Spectrum Disorders, epilepsy, physical disabilities etc)* | |
| Please provide a brief description of behaviours that are displayed by the service users which can present as a challenge to the service: | |

*If you have any questions about this questionnaire, please speak to the researcher.*

## Appendix 7: Interview Schedule

**Introduction**

Interview Schedule

* Thank you very much for coming to speak to me today.
* Do you have any questions about anything at all on the information sheet?
* How are you feeling about talking to me today? Do you have any concerns about talking with me today?
* Is there anything I can do to make it feel more comfortable or reassure you?
* It’s important to let you know that these questions are in no way a judgement or evaluation of your work, they are simply to find out about your experience of using PBS in practice.
* If you want to stop the interview at any time, please let me know.
* If you want to take a break for any reason at any point, please let me know and we can do that.

**Confidentiality**

As explained in the information sheet, everything that we discuss today will be treated confidentially. The only reason I would need to involve anyone else in our discussion today or tell anyone else anything that we talk about is if you told me that you, or someone else were at risk of harm. If that did happen, I would discuss it with you before talking to anyone else. Do you have any questions?

I will also ask you to fill out a brief questionnaire with some questions about yourself, the service you work in, and the service users you support. This information will be kept anonymously, so that other people should not be able to identify you or the people you support from the information. Do you have any questions about that?

Are you ok to start the interview?

**Interview**

*Positive Behaviour Support (PBS): To start with I will ask you some general questions about PBS.*

* What is your understanding of PBS?
* Why do you think services use PBS?
* Have you received any training in PBS? How did you find that?

*Probe if required: Tell me more about your experience of training? What impact did training have for you / for the service / for service users? (Probe added to aid exploration of this question)*

* What do you see as the benefits (if any) to service users?
* What do you see as the disadvantages (if any) to service users?

*Context to implementing PBS: I will now ask you some questions about the service where you work and how PBS has been implemented here.*

* Can you tell me a bit about the service you work in now?
* Can you tell me about how PBS has been introduced/implemented in the service?

*Probe if required: How have you found the process of PBS being introduced / implemented? (Probe added to aid exploration of this question)*

* How does PBS differ to your previous practice, if at all?
* What changes, if any, have you noticed over the time of PBS being introduced to the service?
  + Prompt: Can you give me an example of how that has worked in practice?
* What, if anything, helped you to start using PBS?
  + Prompt: What did you experience as most helpful?
  + Can you give me an example?
* What challenges did you experience when you started using PBS, if any?
  + Prompt: What did you experience as most challenging?
  + Can you give me an example?
* What helped you overcome these challenges?
* How were these challenges managed by the team and/or senior staff?
* Are there current challenges and how are these managed?

*Experiences of implementing PBS: Next, I will ask you some questions about how you found the implementation of PBS, including your perception and how you feel about it.*

* How do you feel about the use of PBS in your service?
* Did the way you feel about PBS change over time? If so, how?
* How do you feel senior staff managed the change(s)?
  + Prompt: What did you find most helpful about their approach? What did you find least helpful?
* How do you feel others in the service managed the change(s)?

*Prompt: How do you feel junior staff in the service managed the change(s)? (Question added following discussions of differences between levels of staff members with participants)*

* Did you talk to senior staff about your feelings towards PBS?
  + Prompts: If so, how did you do that? How did they react? What was the effect of their reaction?
* Did you talk to others about your feelings towards PBS?
  + Prompts: If so, who? How did you do that? What were their responses?
* How did other staff perceive the change? Were their reactions similar or different? How?
* Do service users family’s influence the use of PBS at all? If so, how? *(Question added following discussions of family involvement with participants)*

*Sustaining the change: Finally, I will ask you about how the use of PBS is maintained in the service, including what has been difficult with this and what has helped.*

* How is PBS adapted to suit the needs of the service and/or service users?
* How have these adaptations changed over time?
* Do you feel the use of PBS has been maintained over time?
  + Prompt: If so, what helped this? If not, why do you think that is? What could have been done differently to support the maintenance of PBS?
* How able do you feel to adhere to the PBS plans? *(Question added as theme around the impact of the plans and adherence began to emerge from the data)*
  + What makes it easier to adhere to the plans?
  + What makes it more difficult?
* How does the environment support the use of PBS, if at all? *(Question added following discussions of impact of environment with participants)*
* How is the effectiveness of PBS monitored, if at all? *(Question added to explore this theme following researcher’s reflection of the process of sustaining PBS implementation)*
* What is most helpful in supporting the use of PBS?
* What challenges are there to maintain PBS?
* How are these challenges dealt with?
  + Prompt: What do you think is needed to overcome these challenges?
* How have senior staff supported the maintenance of PBS?
  + Can you give an example?

**Debrief**

* How did you find talking to me today?
* Is there anything that we have not covered that you think is important or that you would like to tell me about?

*What will happen next* – I will be talking to a number of other people and asking them similar questions. I will listen to each interview and transcribe them. After I’ve done that, each recording will be deleted. The transcribed file will not have your name on it. I will analyse all of the written interviews, looking for themes and links. Then I will write them up into a thesis for submission. I will come back to the service to talk about my findings.

* Do you have any questions about anything that we have talked about or the study in general?
* Would you like to receive information about the study findings directly?
* Would you like to give feedback on the interview process?
  + If so, how is it best to contact you?
* Would you like to be involved in the overall development/give feedback on the model, once interviews are complete?
  + If so, how is it best to contact you?

## Appendix 8: Consent Form

**Department of Psychology, Royal Holloway, University of London**

**Surrey and Borders NHS Foundation Trust**

IRAS ID: 238871

Participant Identification Number for this trial:

**An investigation of Positive Behaviour Support in Social Care Settings**

**CONSENT FORM**

Title of Project: Professional carer perceptions of barriers and facilitative processes in implementation of Positive Behaviour Support for adults with learning disabilities

Name of Researcher: Jessica Matcham

Please initial box

1. I confirm that I have read the information sheet dated 20/06/2018 (version 3) for the  
   above study. I have had the opportunity to consider the information, ask questions and have  
   had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time  
   without giving any reason, without my employment or legal rights being affected.
3. I understand that relevant data collected during the study may be looked at by individuals

from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in

the research. I give permission for these individuals to have access to these data.

1. I agree to my interview being tape recorded.
2. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person Date Signature

taking consent

## Appendix 9: Example Transcript

|  |  |  |
| --- | --- | --- |
| **Transcript** | **Initial Codes** | **Focused Codes** |
| **I: Yea, okay, and why do you think that services use PBS, do you think?**  P: Erm I think it’s easier to read, it’s easier to refer to erm a lot of care plans that you get can be quite erm repetitive or quite tedious to read through and during a period, a moment in time if you’re having to refer to it, it’s colour coordination and stuff helps you to try and pinpoint where that person is and what things you can implement at that point in time.  **I: And have you, have you got an example of that? Of a strategy that you implement?**  P: Erm yea I suppose like, I suppose we’ve got a low, a low sort of level trigger, or the person is showing a low level of anxiety, erm that might show up in between green and orange so in the PBS, and then it will give you sort of erm things you can do to help that person during that time, so erm identifying what the trigger is and removing it from the person or from that person’s sights so it’s no longer causing erm that stress, erm and that’s sort of one way… and giving that persons sort of praise for reacting and being able to manage themselves, before it escalates further  **I: Yea, that sounds good, and erm you said that you’ve had some training in PBS…**  P: Yea we’ve done an online course  [...]  **I: How did you find that?**  P: Erm I’m trying to think back at it really… I think it helped the document to make more sense, erm cause when I first saw the document it just seemed like… I could understand generally what it was about but erm it helped to sort of erm break it down, yea actually I should actually do the training or look at it again, I can’t actually remember what it was about to be honest with you  **I: That’s okay, yea I know it can be hard to hold all those things it mind sometimes over… did you say you did it last year?**  P: It was last year, but I was trying to think… I remember it was quite lengthy, there was a lot to sort of read through and there were questions at the end of it  **I: Do you remember how long it took roughly, was there sort of a set time or…**  P: It’s not a set time, you sort of go through the slides and things, I think it took a good part of an hour or probably a bit more  **I: Okay, yea**  P: And then you have the questions at the end  **I: Yea, and you said that it helped you sort of make a bit more sense of the document…**  P: Yea it helped me to understand what the document was about, cause to me it was just a document that was there. A lot of the information which was in the care plan, so it’s sort of replicated there, but it kind of breaks it down into individual interventions for different things, erm so it made me understand why it’s there and how it can be useful to other people  **I: Yea, and so what impact do you think, having done that training, what impact did that have on your everyday practice and the service here, working with service users?**  P: Well after doing the training, it’s something that we refer to as a quick, as a quick sort of, like a quick… if you’re stuck with something or someone’s doing something that you’re not too sure, or this hasn’t worked, you kind of look at PBS and think okay what things we haven’t tried yet and what could this be, so erm people do refer to it erm but I think the, the most important bit is sort of keeping things at a minimum, so rather than waiting for someone to become anxious to the point where you know, it’s it’s obvious that this person is distressed, you’re sort of looking out for a lot more lower level things erm and you’re doing early intervention and stuff like that, rather than just managing a crisis or waiting for them to get to a crisis point  **I: Yea, so sort of acting proactively and…**  P: Proactively yea, it’s like early identification of any triggers and changes in mood and behaviour  **I: Okay, and what do you see as the benefits of PBS, if any, to service users? Why is it good for them?**  P: Erm, I guess, I mean especially for the guys that we look after who have communication difficulties, it’s a way of, it’s a way of, for them I guess it’s knowing that it’s it’s, in a way giving them a voice, so they’re saying okay so if I’m doing this, this is what it means for me or this is what might be upsetting me, and erm it’s it’s, I’m sure the guys might not know what PBS is but it’s you know, it’s kind of a way of them communicating or having their needs met at an early stage, erm like for one of the gentlemen that we look after he’s very sensitive to cold and that can lead on to other things like other things so PBS is sort of it shows you what might he act like when he’s cold and that sort of stops things escalating so I guess it facilitates communication for them as well  **I: Yea, and what do you, erm, what do you see as any disadvantages of using PBS, if there are any?**  P: Erm, I think the disadvantage is because we use care plans and care plans are part of nursing practice, erm and the information is very similar what you would care plan erm it’s, there’s a risk that things which are in the care plan might get missed out of the PBS or things that the PBS… because it’s almost like a duplicate of the same thing, so sometimes what you, you know the care plans are getting updated all the time but the PBS is at risk of not getting done because you’re concentrating on getting the care plans done because they get looked at more often, so I’m guessing that might be a risk, you could sort of over look things on there | Thinking about PBS plans being easier to read than care plans. Thinking about care plans being quite repetitive. Thinking about care plans being quite tedious. Finding colour coordination helpful to pinpoint things to implement.  Thinking about different levels of anxiety. Giving you things you can do to help. Identifying triggers. Removing triggers. Giving the person praise for managing themselves. Preventing escalation.  Training online.  Finding training helped document make more sense. Thinking training helped to break the document down. Thinking they should do the training again.  Being trained last year. Remembering training as quite lengthy. Having a lot to read through in training. Having questions at the end of training.  Not going through training in set time. Taking an hour or more to do training.  Having questions at the end of training.  Finding training helpful to understand the document. Thinking a lot of information was replicated in care plans. PBS breaking down interventions for different things. Training making them understand why PBS is there. Understanding how PBS can be useful to other people.  Having something to refer to quickly. Thinking about being stuck with someone. Looking at PBS when stuck. Thinking about things they haven’t tried yet. Thinking about what the behaviour could be. Referring to the PBS. Seeing keeping things at a minimum as most important bit. Looking out for lower level signs of distress. Doing early interventions rather than managing a crisis.  Working proactively. Thinking about early identification of triggers. Looking for changes in mood and behaviour.  Thinking about SU having communication difficulties. Seeing PBS as a way of giving SU a voice. Thinking about what SU is saying with behaviour. Thinking SU might not know what PBS is. Seeing it as a way of SU communicating. Seeing it as a way of SU getting their needs met at an early stage. Thinking about sensitivity to temperature. Thinking about coldness leading to behaviours. Thinking about things that stop things escalating. Facilitating communication for SU.  Thinking about care plans being part of nursing practice. Having similar information in care plans and PBS. Being a risk things might get missed due to overlap in care plans and PBS plans. Duplicating the same thing in care plans and PBS plans. Updating care plans all the time. Being a risk PBS plans won’t get updated if concentrating on care plans. Looking at care plans more often. Overlooking things in PBS plans. | Having easy to read plans  Having ways of working with people  Developing understanding through training  Turning to PBS when stuck - Having ways of working  Understanding principles of PBS  Valuing PBS  Additional admin adding to workload – keeping plans accessible and simple |

## Appendix 10: Example Memo

06/11/2018

Whilst coding interview 2 I am intrigued by the overall positive view of PBS. This is consistent with the first interview. Interestingly, participant 2 has a focus on the use of medication, or reduction in use as a result of PBS, whereas this wasn’t as prominent in the first interview. This makes sense given that participant 2 is a nurse and participant 1 was a deputy manager. Throughout both interviews there participants spoke about service users warmly and considered what was best for them, whilst also thinking about their professional duties and responsibilities to manage risk.

Participant 2 reflects on differences between previous background in mental health and current work in ID services. I wonder whether this change in field helped them to have an open mind in regards to learning a new approach, such as PBS?

11/01/2019

Following interview 5 I was struck by the kindness and warmth in which the participant spoke about service users. Participants continue to show a positive view of PBS and value its use in the service. Participant 5 spoke about wanting to be appreciated for the work that they do and how this can be achieved through praise from staff but also feedback from service users, such as getting a smile from them or seeing them learn a new skill.

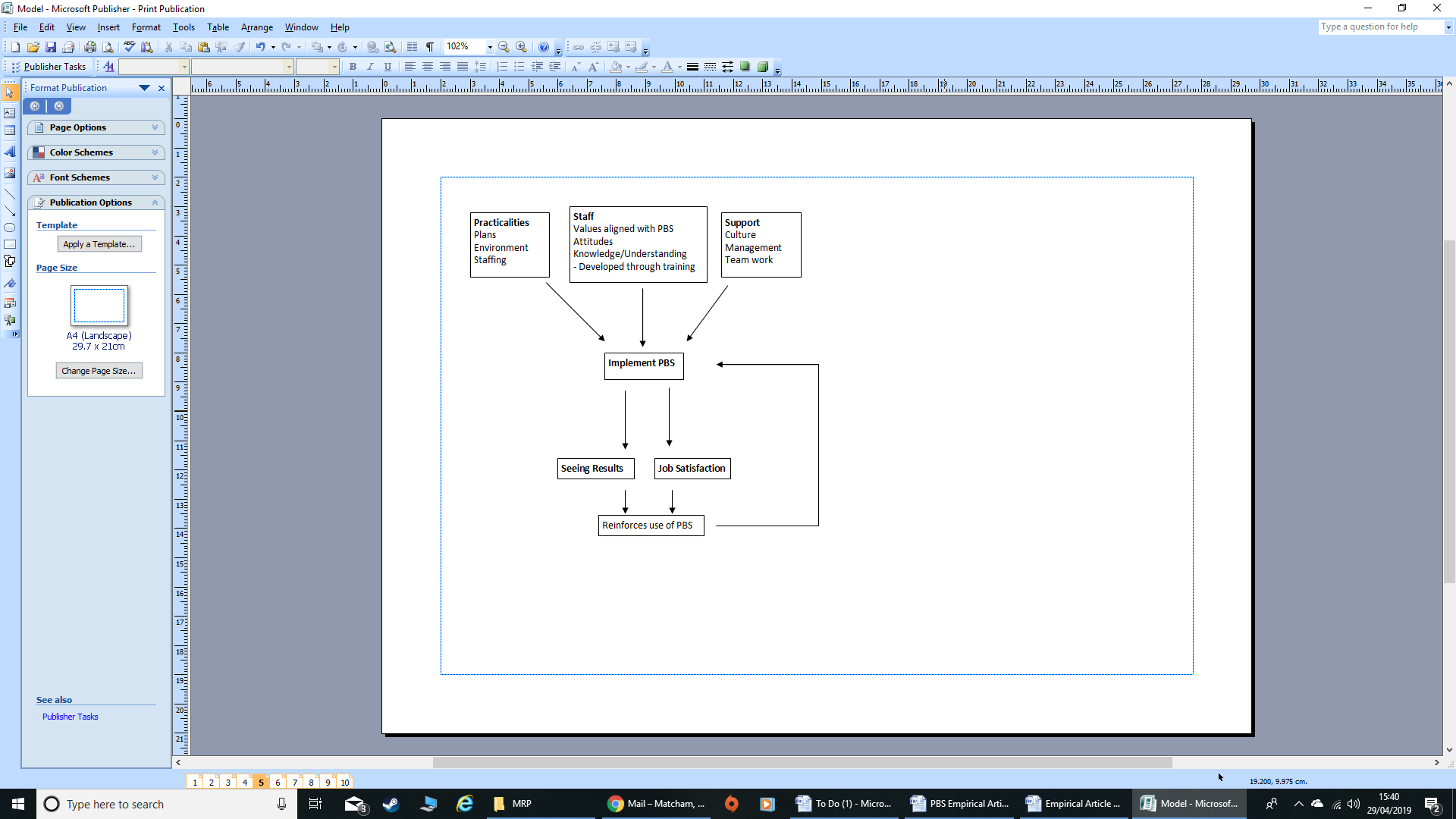
Participant referred to the climate as a trigger for challenging behaviour. This made me think about the impact of the environment, which hasn’t been mentioned by participants previously. Ecological factors is component of PBS so might be worth considering asking questions specifically about this in future interviews. Participant also referred to the atmosphere of the service, and how service users sometimes want peace and quiet.

08/02/2019

Participant 10 brought up many similar themes to previous interviews, including needing to get to know the individual you are working with, needing to be consistent, wanting more time to keep up to date with plans. They also spoke about finding it easy to implement PBS because it was a brand new approach for them (coming from a different field of work previously). This made me think back to participant 2, who moved from mental health or ID services and whether being new to a field makes it easier to pick up current practices. This also links to people’s ideas about longer term staff being more resistant to change.

## Appendix 11: Model Development

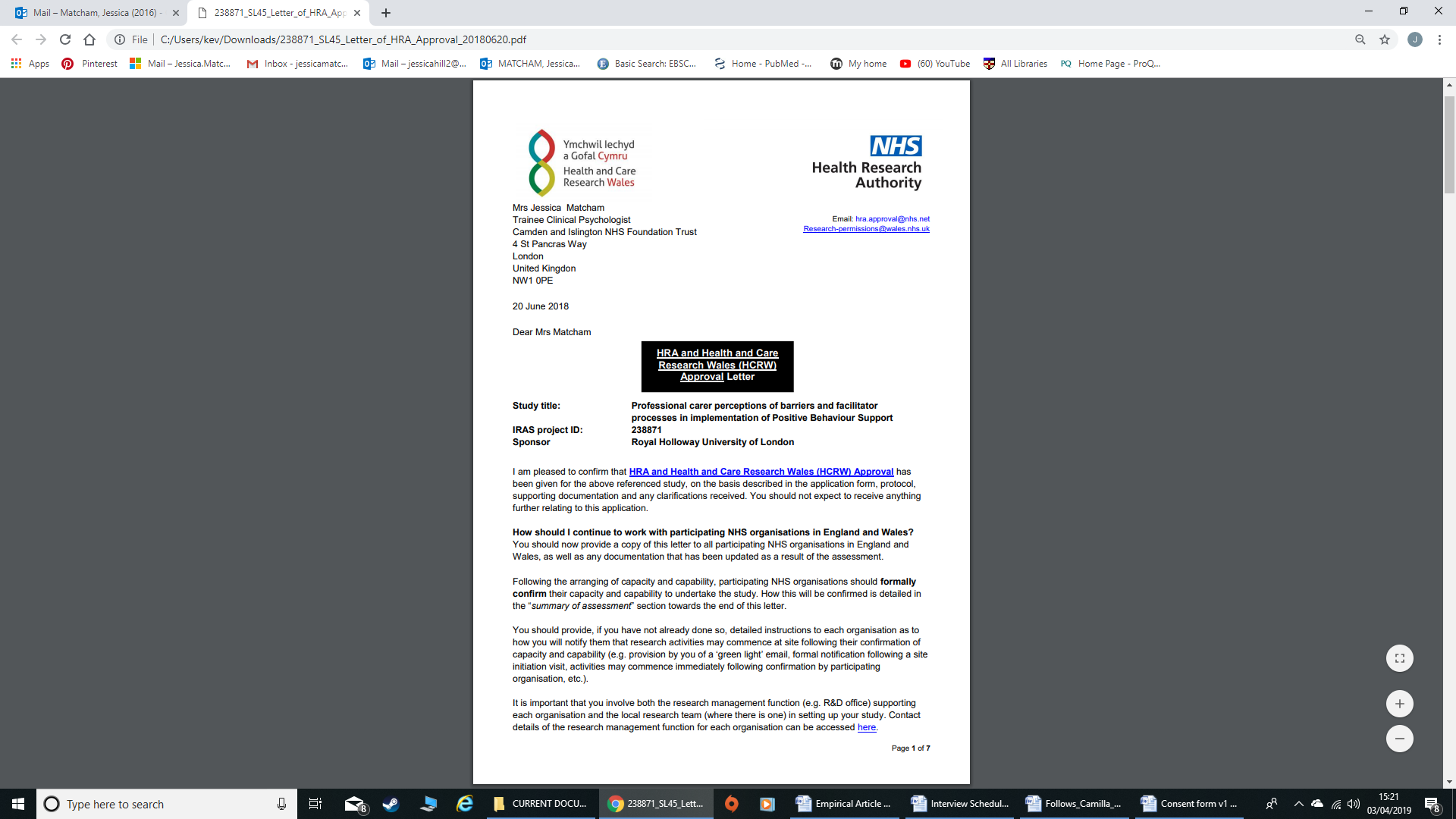
Initial Model for Consultation with Participants, Community Team for Adults with LD and Project Supervisors

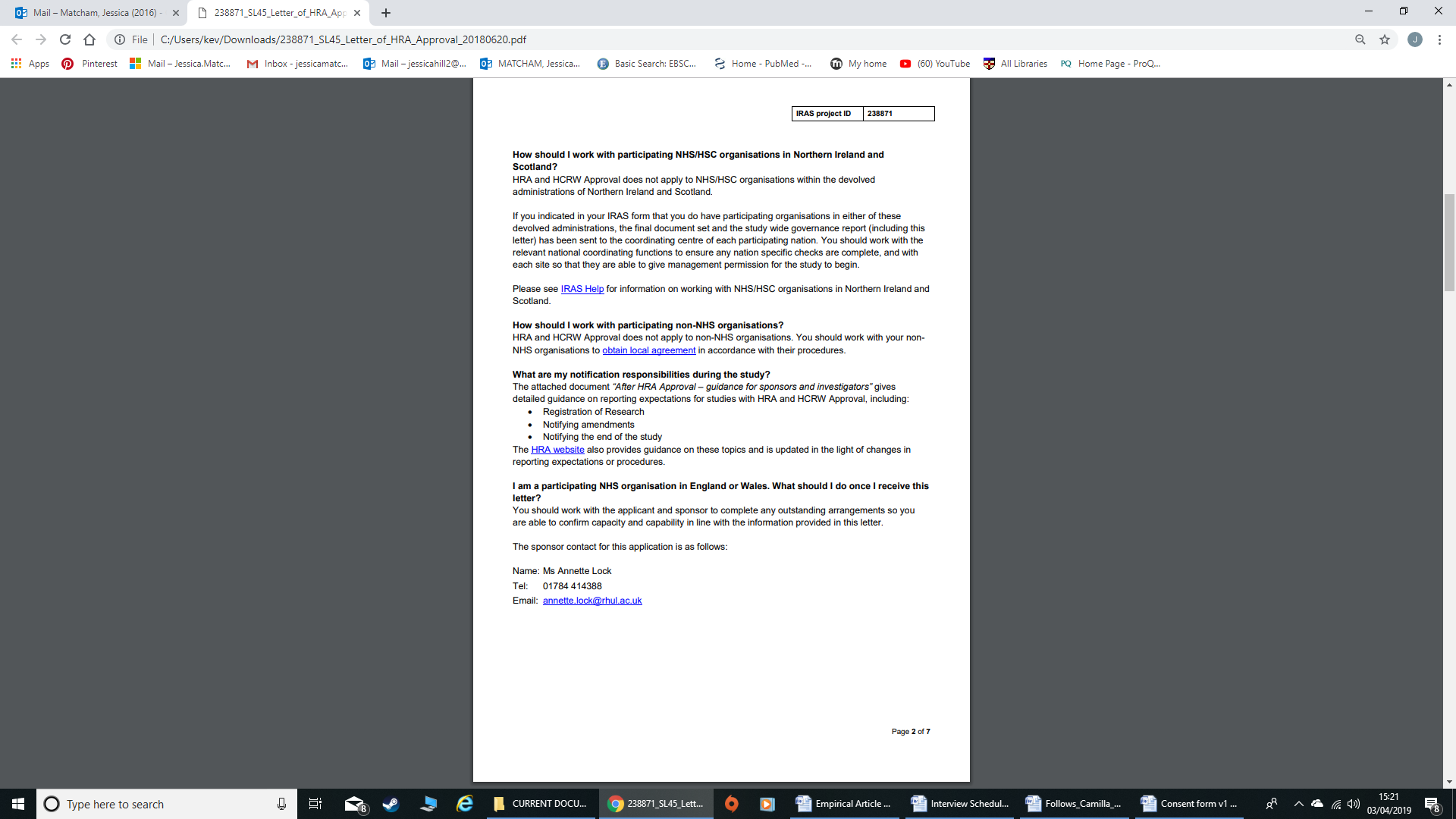


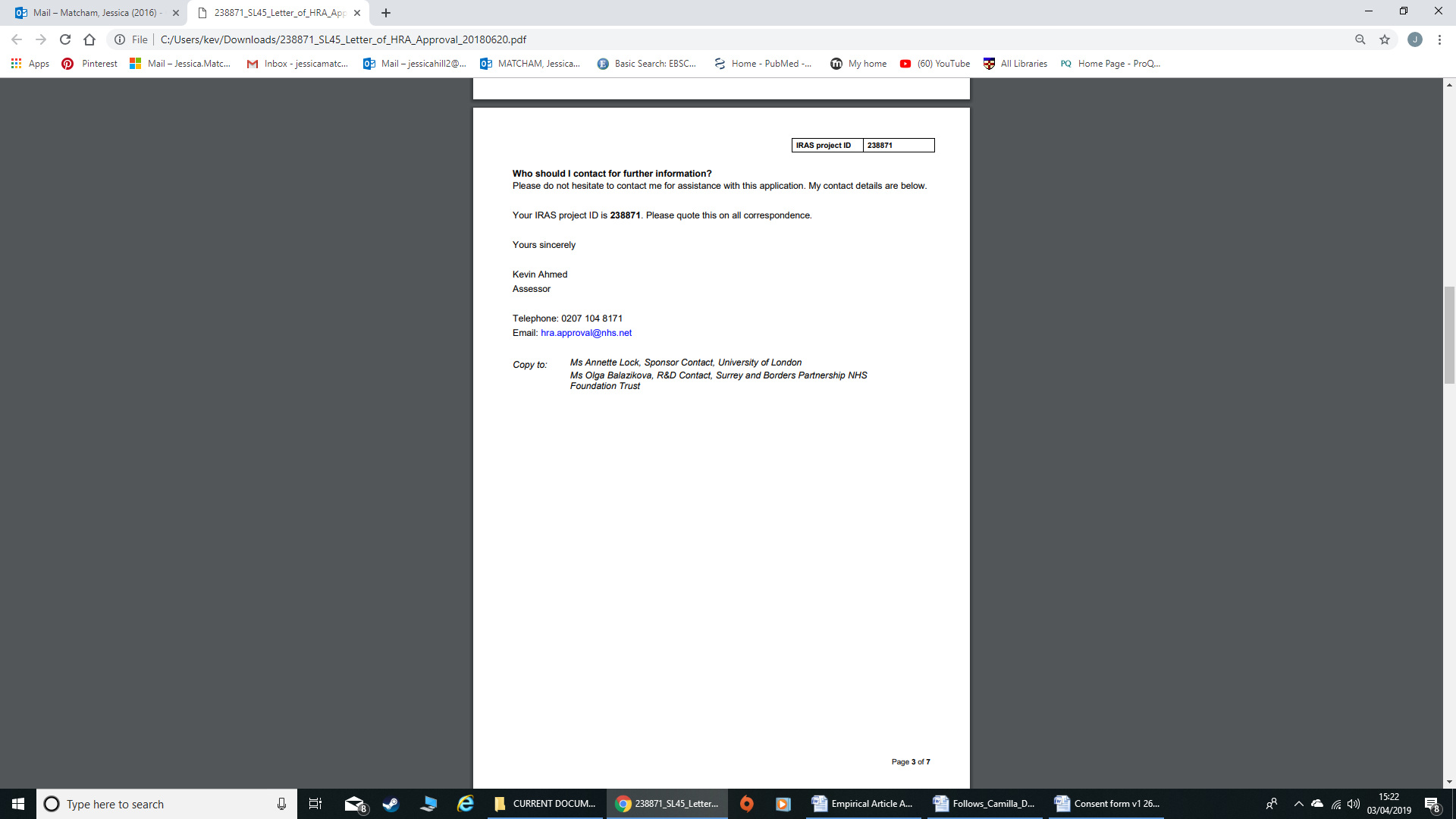
Examples of changes/ideas following consultation and reflection on feedback:

* Bidirectional and systemic relationships between staff, practicalities and support
* Importance of the reinforcement loop
* Inclusion of ‘taking time’ as a its own theme
* Display theoretical themes only and use narrative description to explain how focused codes fit within the model

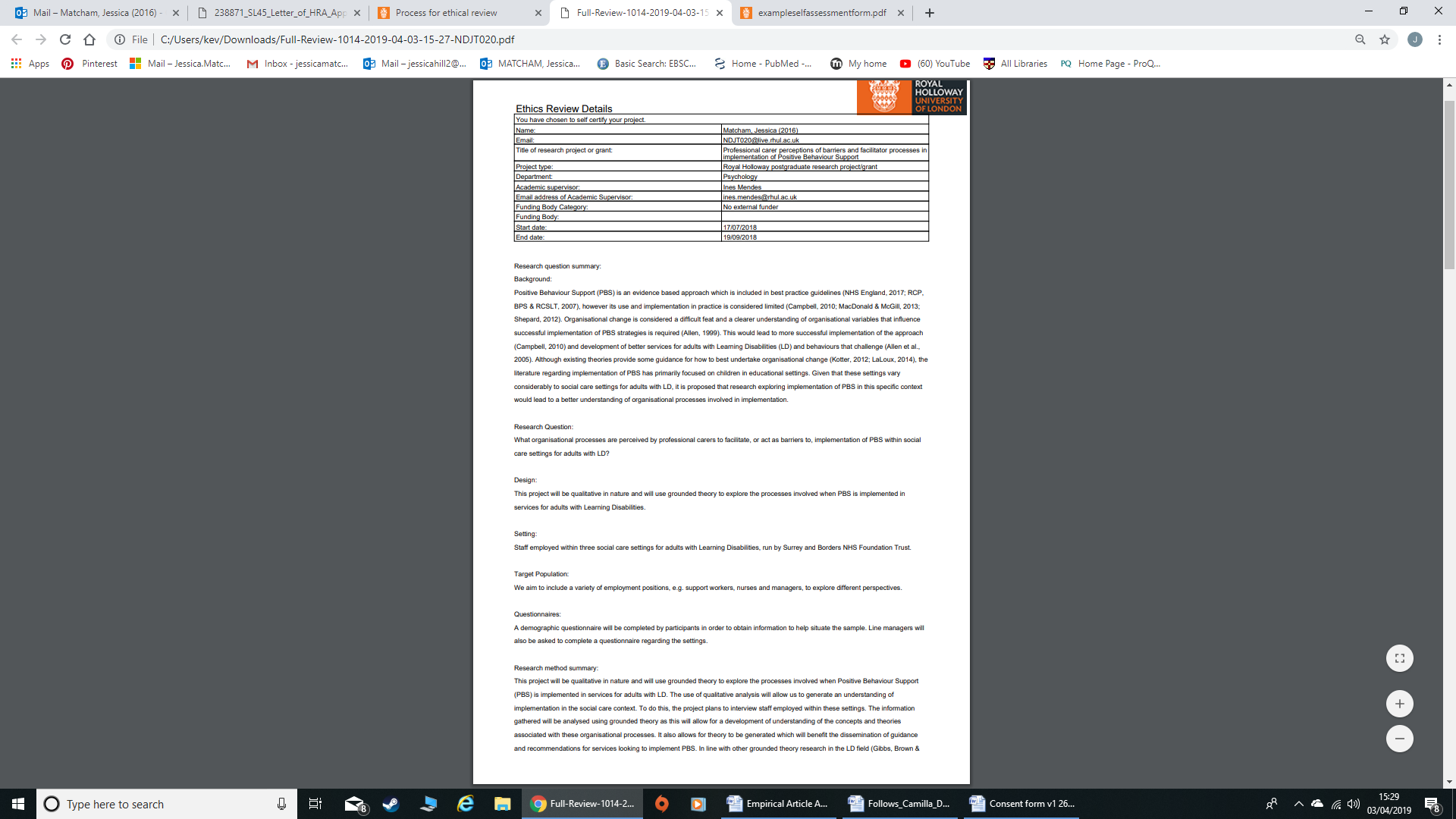
## Appendix 12: Ethics Approval – IRAS

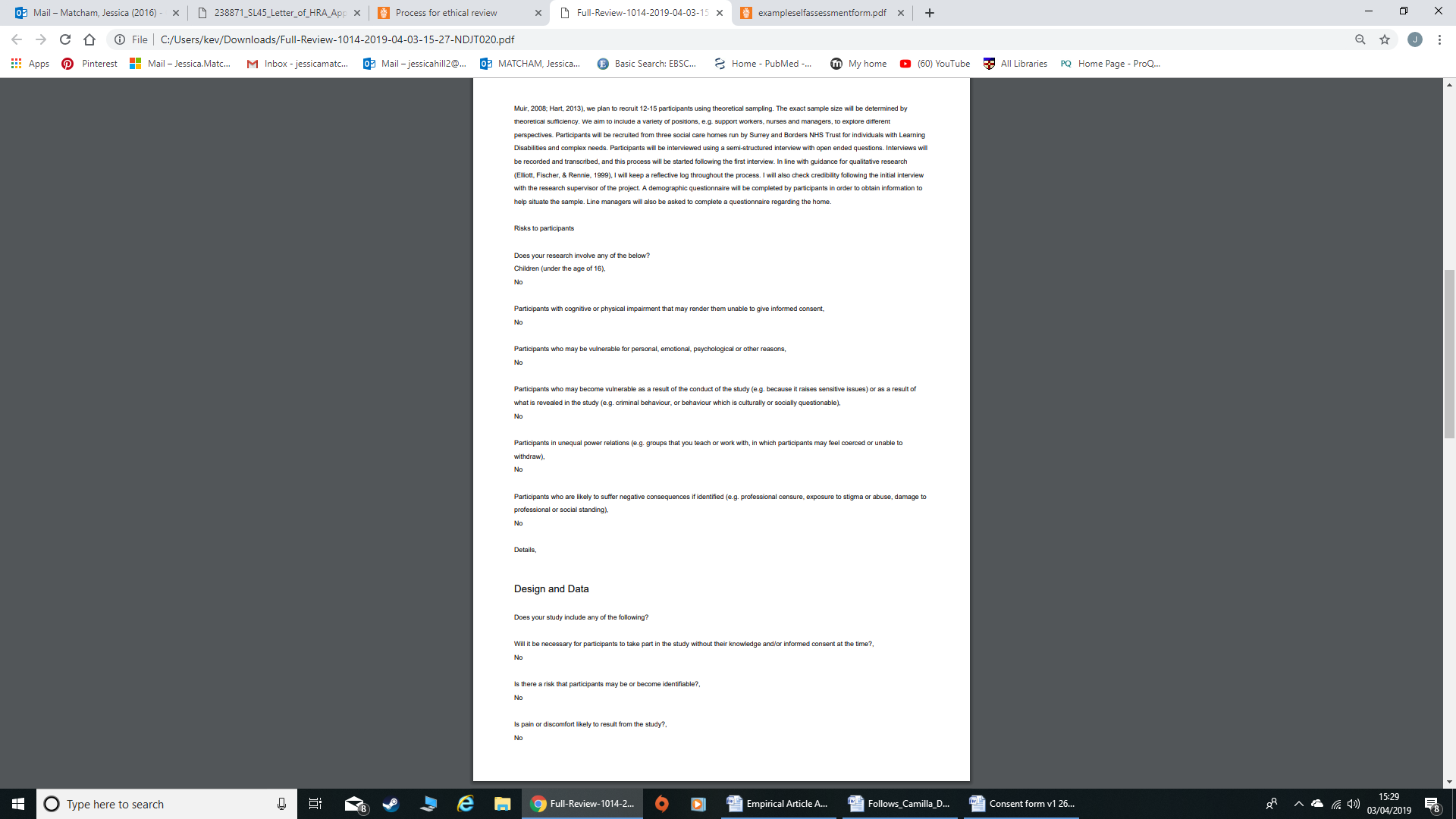
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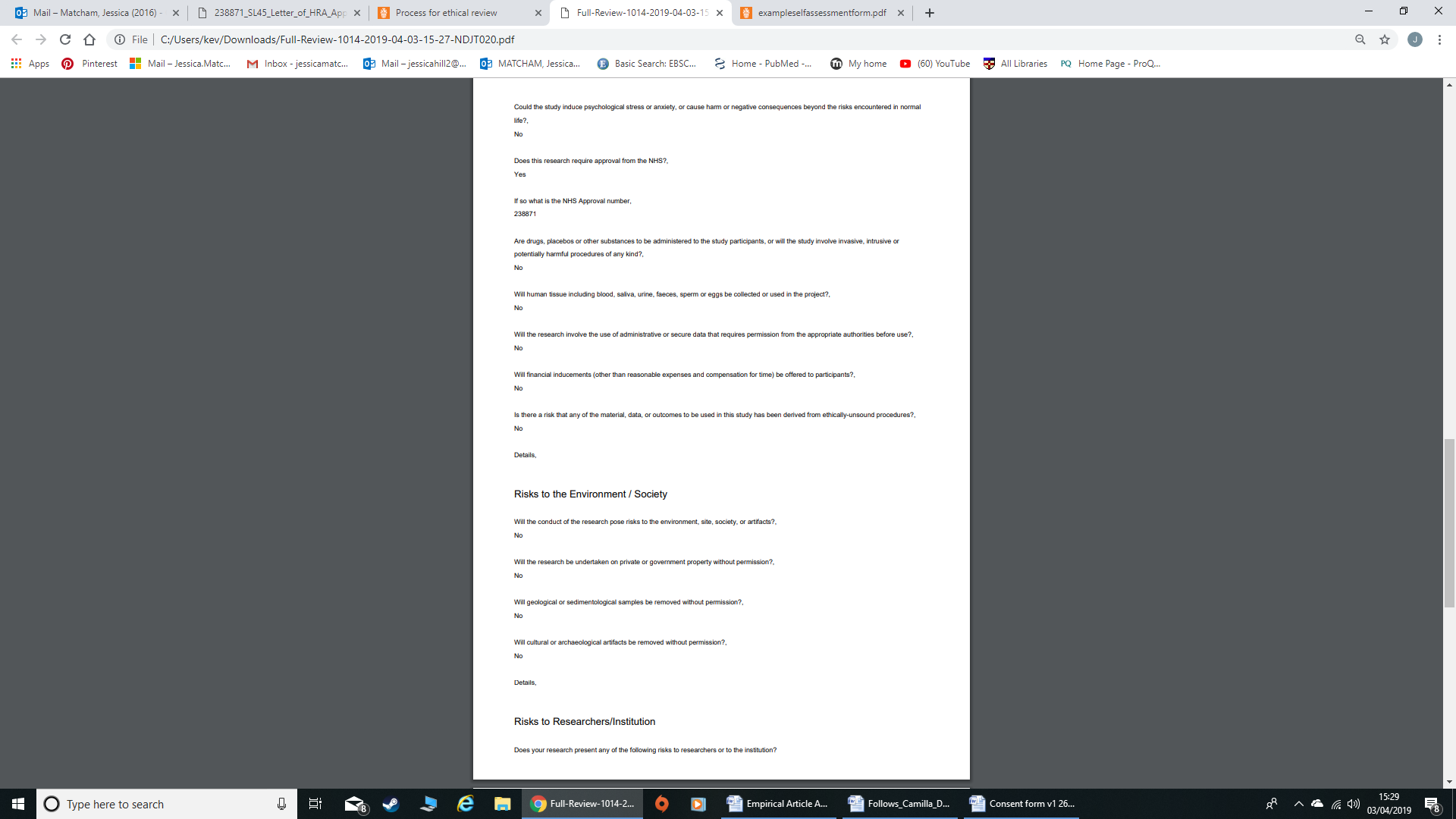
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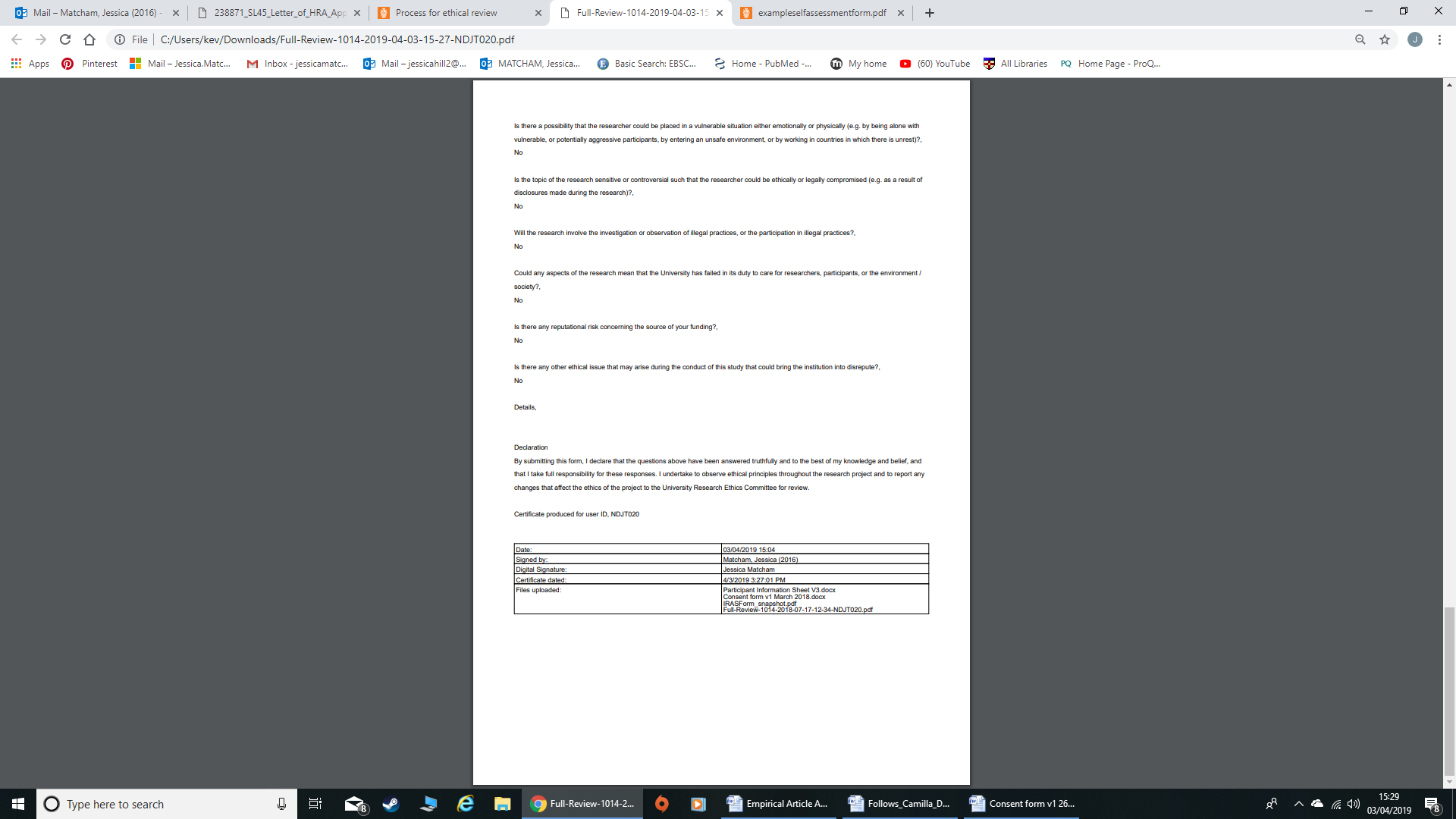
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## Appendix 13: Ethics Approval – RHUL self-certify

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