DEVELOPMENT AND NATIONAL INTEGRATION OF A POSITIVE BEHAVIOUR SUPPORT HOLISTIC PRACTICE FRAMEWORK FOR AUTISM PRACTITIONERS

LISA ALCORN

DProf **November 2017**

DEVELOPMENT AND NATIONAL INTEGRATION OF A POSITIVE BEHAVIOUR SUPPORT HOLSITIC PRACTICE FRAMEWORK FOR AUTISM PRACTITIONERS

ABSTRACT

Positive Behaviour Support (PBS) has evolved over the past two decades and in 2014 it received UK government endorsement as the chosen health and social care practice model *Positive and Proactive Care: reducing the need for restrictive interventions* coincided with this evolutionary development.

In the UK, the Winterbourne View Care Home case was the main reason for improving the support of people with living with autism. From a pragmatic perspective the majority of autism practitioners undertake only what lies within their immediate scope of practice. Without established practice standards, organisational policy and practice has the potential to be misinterpreted and wrongly applied. Understanding these key pragmatic attributes of effective care for practitioners is crucial in protecting vulnerable people; this study investigates the rhetoric and reality of what has been lost in translation at organisationally macro, meso and micro levels.

PBS enables the recognition that in order to ensure quality of life and restrictive practice reduction, a focus on leadership and management is critical. The '*Holistic Positive Behaviour Support Practice Framework for Autism Practitioners'* focuses on promoting tangibly effective PBS and autism practice through leadership training.

An ecological systems theory perspective is considered and synthesised within situational analysis as a methodology. A mixed methods approach is adopted in a single social care organisation in the UK that provides autism services. Semi-structured interviews were undertaken with 8 leaders and managers to extrapolate policy and practice interpretations. 48 autism practitioners engaged in focus groups and the completion of questionnaires. Leaders and practitioners were re-tested to capture the impact of the PBS framework. Practitioners completed pen portraits to provide information on the qualitative impact of the PBS Framework in practice. Discourse analysis and reflexivity were considered to be essential approaches to extrapolate findings and complement the situational analysis.

79% of practitioners considered organisational policy to have improved, alongside levels of incident recording improved by 96%. The qualitative outcomes captured holistic improvements to quality of life for people with autism and relevant wider societal outcomes in statutory regulation and compliance.

ACKNOWLEDGEMENTS

I would like to thank Dr Catherine Hayes and Professor Helen Edwards for their support and guidance through supervision, and their generous investment of time throughout this process. I would also like to thank Dr John Fulton for his candour during my annual doctorate reviews.

I am very grateful to my colleagues Ashley Gibson (PBS Lead Practitioner) and Andy Lees (Positive Behaviour Support Manager) who have demonstrated their passion and commitment to this framework and diligently helped in proofreading and offering me encouragement.

To my parents Brian and Margaret Fenton for giving me a strong work ethic and believing in me, I hope I have made you proud parents!

I am very grateful to my husband Gavin and children, Emily and Adam, for their endless patience and allowing me the time to explore and develop this PBS Framework. In your own way, you have all contributed to making a difference to the lives of people with autism and their support staff.

Finally, to all the people with autism that I have had the pleasure of knowing and particularly the young man who helped me confirm my commitment to developing Positive Behaviour Support. The lessons you have taught me will now be shared with the autism community and beyond.

TABLE OF CONTENTS

ABSTRACT **2**

ACKNOWLEDGEMENTS **3**

CHAPTER 1: COMMUNITY OF PRACTICE **9**
1.1 Introduction **9**
1.2 Community of Practice **9**
1.2.1 The domain 10
1.2.2 The community 10
1.2.3 The practice 11
1.3 Contribution to Practice and Impact **13**
1.4 Transferability of the PBS Framework to other Clinical Fields **15**
1.5 Dissemination **16**
1.6 Conclusions **17**

CHAPTER 2: AIMS OF THE RESEARCH **18**
2.1 Introduction **18**
2.2 Background and Motivation of the Research **18**
2.3 Significance of the Research **20**
2.4 The Focus and Aims of the Research **21**
2.5 Research Questions **22**
2.5.1 The micro system 22
2.5.2 The meso system 23
2.5.3 The exo system 23
2.5.4 The macro system 24
2.5.5 The chrono system 24
2.6 Research Aims and Questions Framework **25**
2.7 Anticipated Outcomes within the Community of Practice **26**
2.8 Structure of the Thesis **26**
2.9 Structure of the Doctoral Portfolio **27**
2.10 Learning Outcomes of the Doctoral Programme **27**
2.11 Conclusions **30**

CHAPTER 3: LITERATURE REVIEW **32**
3.1 Introduction **32**
3.2 History of Autism **32**
3.3 Epidemiology of Autism in the UK **35**
3.4 Consequences of Autism **35**
3.5 Autism and Behaviours of Concern **35**
3.6 Autism and Restrictive Physical Interventions **37**
3.7 Cost of Autism in the UK **38**
3.8 Universal Approaches to Prevention **39**
3.9 PBS National Policy Context **40**
3.10 PBS International Policy Context **46**
3.11 Triangulation of Policy Context **48**
3.12 The Lost Translation of PBS Policy **49**
3.12.1 Philosophy and practice of PBS 49
3.12.2 Environmental accommodation 50
3.12.3 Regulation of training 50
3.12.4 Corporate governance 51
3.13 Evolution of PBS – A Critical Evaluation **51**
3.14 Principles of PBS **54**
3.15 What is an Ethical and Person-centred Value Framework? **55**

3.16 Person-centred Philosophy – A Critique **59**
3.17 Ethical and Value-led Training **61**
3.18 PBS as a Treatment Model **61**
3.19 Enhancing Quality of Life **63**
3.20 Critical Evaluation of Leadership and Management Theory and the Integration of PBS into Practice **64**
3.21 Governance – A Systems Theory Perspective **70**
3.21.1 PBS governance 71
3.22 Training a Capable Workforce in PBS **73**
3.23 Conclusions **75**

CHAPTER 4: METHODOLOGY **77**
4.1 Introduction **77**
4.2 Philosophical Foundation **79**
4.2.1 Interpretivist paradigm 79
4.2.2 Epistemological position 81
4.2.3 Ontological position 81
4.2.4 Researcher positionality 82
4.3 Research Ethics **84**
4.4 Epistemological Background of Situational Analysis **86**
4.4.1 Situational mapping 89
4.4.2 Social worlds/arena maps 91
4.4.3 Positional maps 92
4.4.4 Discourse analysis 93
4.4.5 Reflexivity 94
4.5 Mixed Methods **95**
4.6 Data Collection Methods **96**
4.6.1 Semi-structured interviews 96
4.6.2 Focus Groups 97
4.6.3 Questionnaires 99
4.7 Selecting Participants **101**
4.8 Data Analysis **102**
4.9 The Research Procedure **104**
4.10 Authenticity and Trustworthiness **106**
4.11 Conclusions **106**

CHAPTER 5: RESEARCH FINDINGS **108**
5.1 Introduction **108**
5.2 Micro System Situation **108**
5.2.1 Research question 1: what are the key criteria practice benchmark indictors for developing a PBS framework that will enhance the competencies and capabilities of autism practitioners so that autism practices are predictable and offer stability to people with autism? 109
5.2.2 Research question 2: what are the quality of life outcomes from implementing a PBS practice framework for people with autism and the autism practitioners? 113
5.3 Meso System Situation **116**
5.3.1 Research question 3: how does organisational policy impact autism and PBS practice; in particular, how are values, attitudes and norms created when translating policy into practice? 116
5.4 Exo System Situation **119**
5.4.1 Research question 4: what are the required practice standards to achieve UK statutory compliance in services and how can these positively influence the exo-system? 120
5.5 Macro System Situation **123**

5.5.1 Research question 5: how do the interactions and interconnectedness of different policy factors within a PBS context affect practice and what are the dynamics at play that can cause a 'lost in translation' phenomenon? 124
5.5.2 Research question 6: what are the leadership and governance practices required to promote open and transparent cultures, which can help to positively shape the economic and political environment? 127
5.6 Chrono System Situation 129
5.6.1 Research question 7: to what extent do social care influences impact the community of practice? 129
5.7 Conclusions 133

CHAPTER 6: A HOLISTIC POSITIVE BEHAVIOUR SUPPORT PRACTICE FRAMEWORK FOR AUTISM PRACTITIONERS 135
6.1 Introduction 135
6.2 The Holistic Practice Framework Conceptual Model 135
6.3 Conceptual Model – Person-centred 137
6.4 Portfolio Practice Standard 1 139
6.5 Portfolio Practice Standard 2: Policy 142
6.6 Portfolio Practice Standard 3: Ethics 146
6.7 Portfolio Practice Standard 4: Holistic Assessment 148
6.8 Portfolio Practice Standard 5: PBS Planning 150
6.9 Portfolio Practice Standard 6: Risk 152
6.10 Portfolio Practice Standard 7: Effective Reporting and Recording 154
6.11 Portfolio Practice Standard 8: Post Incident Management 157
6.12 Portfolio Practice Standard 9: PBS Practice Development 159
6.13 Conclusions 162

CHAPTER 7: DISCUSSION, RECOMMENDATIONS AND CONCLUSIONS 163
7.1 Introduction 163
7.2 The Purpose of the Study 163
7.3 Discussion of Results 164
7.3.1 Research theme: practice standards 164
7.3.2 Research theme: quality of life 166
7.3.3 Research theme: policy into practice 169
7.3.4 Research theme: practice benchmark indicators for statutory compliance 171
7.3.5 Research theme: interactions and interconnectedness of policy factors 173
7.3.6 Research theme: leadership and governance 175
7.3.7 Research theme: social influences 177
7.4 Implications and Importance of the Findings for the Community of Practice 179
7.5 Limitations of the Research 181
7.6 Recommendations for Future Research 183
7.7 Conclusions 183

REFERENCES 185

APPENDICIES ..... Error! Bookmark not defined.
A: Literature Search 204
B: Governance and Ethical Clearance 205
C: Research Information 207
D: Organisation Letter of Study 210
E: Agreement of Study 211
F: Letter to Participants 212
G: Consent Form 213
H: Semi-Structured Interview Example 214
I: Focus Group Transcript Example 223

J: Interview Protocol Checklist 229
K: Focus Group Protocol Checklist 231
L: Pen Portrait 233
L.1 – William 233
L.2 – Rose 236
L.3 – Ann 240
L.4 – Billy 243
M: Questionnaire 246
N: Code List from Semi-Structured Interviews 248
O: Comparisons of Semi Structured Interviews 254
P: Code List from Focus Groups 259
Q: Comparisons of Focus Groups 266
R: Comparisons of Questionnaires 271

LIST OF FIGURES

Figure 1: Focus of the Research....21
Figure 2: Research Aims and Questions Framework....25
Figure 3: Framework for Reducing Restrictive Practices and Promoting Positive Behaviour Support (Paley, 2012), BILD....72
Figure 4: The Professional Doctorate Research Framework for a Holistic PBS Practice Framework for Autism Practitioners....78
Figure 5: Social World Arena Mapping....91
Figure 6: Positional Mapping....93
Figure 7: Social World/Arena Mapping of Practice Benchmark Indicators....112
Figure 8: Social World/Arena Exo System PBS Practice Standards....123
Figure 9: Positive Behaviour Support Leadership Framework (Alcorn, 2014)....136
Figure 10: Holistic Positive Behaviour Support Practice Framework for Autism Practitioners (Alcorn, 2014)....137
Figure 11: Practice Standard - Leaders....139
Figure 12: Practice Standard - Policy....143
Figure 13: The Positive Behaviour Support Holistic Practice Pathway (Alcorn, 2015) 144
Figure 14: Practice Standard - Ethics....147
Figure 15: Practice Standard - Holistic Assessment....149
Figure 16: Practice Standard - PBS Planning....151
Figure 17: Practice Standard - Risk....153
Figure 18: Practice Standard - Reporting and Recording....155
Figure 19: Practice Standard - Post Incident Management....158
Figure 20: Practice Standard - PBS Practice Development....160

LIST OF TABLES

Table 1: Professional Doctorate Knowledge Outcomes....27
Table 2: Professional Doctorate Skills and Abilities....28
Table 3: Professional Doctorate Learning Outcomes....28
Table 4: A Synthesis of the Ethical Grid (Seedhouse, 2009) and PBS Ethical Principles .56
Table 5: Empirical Studies on Ethical Decision Making....58
Table 6: Comparison and Rationale of the Research Assumptions....79
Table 7: Advantages and Disadvantages of Researcher Positionality....83
Table 8: Ordered Situational Mapping....89
Table 9: Scope of Participants....101
Table 10: Data Analysis Research Structure....102
Table 11: Situational Analysis - Micro System....108
Table 12: Focus Group Questionnaire Outcomes on Attitudes and Experiences....114
Table 13: Situational Analysis - Meso System....116
Table 14: Situational Analysis - Exo System....119
Table 15: Situational Analysis - Macro System....124
Table 16: Ordered Situational Mapping of Different Policy Factors Synthesised with Findings....125
Table 17: Situational Analysis - Chrono System....129
Table 18: Focus Group Questionnaire Outcomes for Capable Environments....132

CHAPTER 1: COMMUNITY OF PRACTICE

1.1 Introduction

Understanding the profession and community of practice is significant in any research, but even more so in a professional doctorate, in which a researcher is required to demonstrate a unique contribution to the profession. Understanding my profession and what is already known, as well as highlighting what is unique, are two key components of this thesis. Demonstrating how and why the work makes a genuine contribution that advances my profession in practical ways is the pivotal outcome.

In this chapter I firstly examine the concept of a community of practice and focus on the research of Lave and Wenger, who were influential in establishing the concept of 'community of practice'. The three characteristics – domain, the community and the practice – are discussed in relation to my research situation. I highlight the importance of being central to the community as a director of operations, rather than being peripheral to the community, which is the essence of the professional doctorate.

Understanding the development cycles of the community and understanding my own professional identity determined the way I addressed the study and how I made sense of the professional arenas in the way that I needed so as to interact with the community. Exploring my contribution to practice and the impact this can make in my community of practice is considered and directed to the relevant chapters within the thesis as a cross-reference guide. The overarching outcomes of the research identified within the community of practice highlight who will benefit from the study and how they will do so.

Reference is also made in this chapter to Chapter 6 of the thesis, which addresses the 'practice framework' that has evolved and which is presented in this study. The Holistic Positive Behaviour Support Practice Framework for Autism Practitioners emerged as a direct result of reviewing the literature, contextualising my own experiences as a practitioner and director and researching the experiences of other leaders and autism practitioners.

The final areas that are discussed in this chapter are transferability of the PBS practice model to other clinical fields. I address the process and structure undertaken in identifying the community arenas where PBS would be most useful and could have a significant impact. Finally, this chapter closes by considering the dissemination of the research findings to a targeted arena of the community.

1.2 Community of Practice

A community of practice is formed by people when engaging in a process of collective learning in a shared domain of human endeavour. According to Wenger (2010) communities of practice are groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly." The outcome of this work is related to

what is considered important to this community of practice and will inform and contribute to its evolution. Wenger (2004) claims in his article 'Knowledge Management as a Doughnut: shaping your knowledge strategy through communities of practice' that practitioners who use knowledge in their activities are the best placed to manage this knowledge. When knowledge is created, practitioners know what to do and what is right; however, when practitioners don't know what to do, this can create trouble and the translation of practice is blurred. The concept of 'community of practice' therefore has a significant importance and is the social fabric of knowledge.

Wenger argues that there are three characteristics of a community of practice. These three domains are discussed in relation to my community of practice in which the research is located and are discussed below.

1.2.1 The domain

This research is centred on a UK national social care organisation that specialises in supporting adults (18-65 years) with autism and associated learning disabilities. All present with behaviours of concern, e.g. aggression towards themselves, others and their environment. These services support the most vulnerable people on the autistic spectrum who are at risk of restricted physical intervention practices being implemented regularly.

1.2.2 The community

The community are practitioners who provide services to people with autism. These include regional directors, service managers and support workers. This community is extended to people with autism themselves; these are individuals who each have a unique history of living in various services, in hospitals, residential homes and/or family homes. Many have arrived as a result of a breakdown of other organisations and therefore have numerous learnt negative behaviours, psychological and emotional difficulties.

All regional directors and some service managers hold professional qualifications in social work, learning disability or mental health nursing. Most junior staff have completed the mandatory qualifications outlined in the Care Certificate, which is a set quality standard qualification in care, although none have qualifications specific to autism. All staff have completed autism awareness, challenging behaviour and physical intervention training. Directors and managers have undertaken autism and behaviour training within their careers, however, most are out-dated.

The managers overseeing the day to day operations of these autism services in all cases have had careers in challenging behaviour services, albeit experience rather than academic. The directors involved in the study have come from varying backgrounds; some have been managers in similar autism services and others have never directly managed or worked in community settings, instead coming from health services such as long stay hospitals or from local authority social work.

The current working situation of this community presents with high service turnover, especially at support worker level, and recruitment is known to be problematic. This is largely due to the fact that the level of experience required for supporting the complex needs of people with autism are lacking. Challenging behaviour is cited by these practitioners as the main factor for leaving. People with autism are therefore presenting with more behaviours of concern due to staff lacking understanding. As a result, directors and managers are pressured to maintain quality services with quality and practice being considered by these practitioners as the main focus of their responsibilities and stressors. Staff sickness remains high in this community as a result of burnout and high stress levels as the main causes.

There is consensus among practitioners that the current professional working context consists of a number of factors:

- Training is inadequate for the complexities of the people they support;
- Staff do not have the skills and knowledge necessary;
- Lack of understanding of the individuals' autism profile;
- High usage of restrictive physical intervention;
- High levels of staff injury;
- Placing authorities too reactive and also unresponsive when services are struggling;
- High levels of crisis and breakdowns in service provision, resulting in people being sectioned.

There is a belief within this community that funding for people with autism is insufficient and environments are not fit for purpose. Directors and managers also believe that they require more understanding of autism and behaviour in order to provide the complex support required for services and they often feel out of their depth when making decisions.

There is an agreement among all practitioners that they continue to work within this context because of their shared values, attitudes and commitment to continue to try and improve the lives of people with autism. The relationships they have formed with these people and within their teams are what makes them continue on this career path.

1.2.3 The practice

Although many would assume that supporting people with autism should be a skilled and professional practice, what this community in fact presents in its current context is quite the opposite. A large amount of routine practice is unskilled but still requires interaction and sense making in order to get the job done. When not considered from an autism context, means that practices are not fit for its community and domain and can result in behavioural challenges.

As a result of this, the 'community to practice' loses its sense of purpose, direction and, most importantly, its shared beliefs and motivation. Practice becomes unstructured and inconsistent for both the person with autism and the procedures within the organisation. Therefore, what often occurs is frequent reorganisation of practice and a lack of engagement and relationship

building between the person and their staff. Leaders, managers and staff do not have ownership over their community of practice as they do not have a commitment to these procedures. The outcome of this is that the practitioners within the community start to individualise this practice and the practice is fragmented due to no collective engagement. Consequently, practice is stifled, overlooked, and even lost. Leading and managing becomes a peripheral occupation and innovation that impacts best practice.

Lave and Wenger's (1991) seminal work on 'legitimate peripheral participation' has a significant role at the point of practice. In essence, in order to truly make a contribution to practice, the practitioner needs to move beyond the rudiments of embryonic practice and towards the centre rather than remain on the periphery of the practice community.

My own role as director of operations allowed me to participate centrally. Throughout my career I have worked in challenging behaviour services, all of which specialised in autism. I have experienced this from the perspective of a support worker through to director level, spanning 25 years. Over this timeframe there have been numerous changes in the legal, social and economic context, as well as with regard to understanding autism. However, the practice of autism has not been kept in alignment with these changes, as will be discussed in Chapter 3.

My own position was created to directly challenge autism and behaviour practice across a national organisation. Within the national environment of increasingly complex autism referrals, closures of long stay institutions and the transformation of the care agenda becoming more evident, my role focused on several areas:

- Improve autism knowledge and practice;
- Embed positive behaviour support knowledge and practice;
- Develop autism and behaviour policies;
- Develop and implement practice development training courses;
- Develop a referral and assessment system;
- Develop reporting and measuring systems for behaviour incidents;
- Reduce restrictive physical intervention;
- Reduce crisis breakdowns and admissions to hospitals.

In my role I was able to directly consider the context, beliefs and motivation within the community of practice so that the development of practice was not only addressed, but it also helped to identify and generate new knowledge in order to create an appropriate 'community of practice' for the future of autism services.

Engaging in peer practice reviews of my written work was useful as it offered both a broader evidence-based context, and also enabled me to develop a learning arena of professionals who could critique my work, whilst also endorsing it. Promoting contextualisation, in order to be credible and authentic, were important components of my written work. This research led me to create my own community of practice with a group of professionals from both

academic and professional backgrounds. This assisted me in understanding the nature of the practice and consequently my professional identity grew in both integrity and reputation.

At various times throughout this study I have found my professional research community to be both motivated by this study and also antagonistic. Using higher reasoning through critical reflexivity helped me to understand where they were coming from. This promoted my skills of persuasion, enabling them to at least consider my ideas and interpretation of the theories. The sound methodology discussed in Chapter 4 helped to shape and convince my community of practice that my theories and PBS interpretation is not only authentic, but also relevant to current practice.

1.3 Contribution to Practice and Impact

The contribution that knowledge makes to practice is one of the most important components of a professional doctorate. This consideration, as well as the following questions from *The Professional Doctorate* (Fulton, Kuit, Sanders and Smith, 2013), provided me with a structure for consideration:

- Who else will use my work?
- What impact on practice can I demonstrate?
- How can I impact upon the practice of others?
- What will other practitioners learn by reading my work?

By fully immersing myself into my community of practice, I succeeded in achieving these questions. Chapters 5, 6 and 7 provide the evidence and outcomes of these questions and shape the doctorate portfolio i.e., the framework.

There is an increasing concern about the 'theory-practice' gap in autism and behaviour practice; practitioners have to rely on their intuition and experience since traditional practice often doesn't seem to fit the uniqueness of the situation, or provide instructions on what to do in complex situations. In Chapter 2, I discuss my experiences and motivation for this research. After experiencing several serious incidents first hand in supporting people with autism and seeing how distressed both the person themself and their staff could become on a daily basis, I was acutely aware of the impact this research would have on the individual and organisational level.

Social care employers and practitioners are responsible for ensuring they are prepared, through policy, training, advice and supervision, to undertake this very complex and demanding work. Yet despite the level of these responsibilities, there is a general absence of good practical guidance that translates policy into practice. The literature review in Chapter 3 highlights the slow progress in the community and how policy has been translated and interpreted in practice, often to the detriment of people with autism and practitioners. Leaders of organisations and their staff are left to interpret statutory and non-statutory guidance and the result of this is far removed and distorted from the true essence of PBS.

An opportunity to correct the theory-practice gap arose in the development of a Holistic Positive Behaviour Practice Framework for Autism Practitioners that is based on sound evidence-based practice founded on academic and research rigor. Practically, this has been tested for more than a decade across UK services, gaining rich tacit knowledge that has latterly been applied academically through the professional doctorate. The overarching outcomes that have been captured are as follows:

- Improving the quality of life of people with autism and their support practitioners;
- Improving the knowledge of leaders and practitioners;
- Improving the governance of organisations and their performance outcomes;
- Improving the culture of supporting people who present with behaviours of concern;
- Improving national performance figures during Care Quality Inspections;
- Supporting the UK Government statutory requirements set out for social care providers and influencing and increasing local and national competency.

Chapter 6 outlines this practice framework and provides the community of practice with a 'toolkit' of practice standards that have been rigorously tested nationally within the community. The holistic practice framework is the first of its kind to triangulate policy, professional practice standards and practice outcomes in order to significantly reduce the theory-practice gap in autism specific services.

Finally, the practice framework is important as it offers further depth and breadth beyond what has already been researched. This research will shift the focus from mundane generic practices in social care and redirect this to focus on autism and PBS practice itself. This context is likely to have benefits in the following areas:

- <u>Reduction in high cost placements and helping to increase the allocation of appropriate resources.</u>

  High cost placements are normally attributed to the severity of a person's behaviour and the number of staff required to control this. Resource allocation for specialist equipment, such as that for sensory needs, is often not available due to funding for staffing taking precedence. Often, however, behaviours occur as a result of the person's sensory needs, such as too many staff in their vicinity. This may seem ludicrous to some, but it is often the reality.

  A reduction in staffing levels would reduce behaviours of concern and allow for the release of funding for more therapeutic resources, as well as possibly releasing funding for other people who currently do not receive support and assistance. Of course, the safeguarding of people would need to be carefully managed.

- <u>Improve national practice capabilities and cross boundary partnerships.</u>

  Improving the national capabilities will contribute to and improve the recruitment shortage of skilled staff across various social care fields. This will hopefully integrate communities of practice more, and in particular improve multi-professional cross

boundary relationships. Currently, we see competing expectations between social and health functions, particularly in learning disability and mental health services. The result of this is differing perspectives and slow response rates that often cause tension. The outcome of this is that people with autism do not receive the appropriate skilled support and their behaviour continues to be affected over time.

There is a belief within the community that social and health practitioners cause conflict in practice due to these differing perspectives. As we are now seeing a more migratory workforce between the two fields, more cohesion is desperately needed due to this added complexity.

- Improve the health and wellbeing of people with autism.

  We have seen the introduction of the Care Act 2016, which focuses on the health and wellbeing of vulnerable people. This research will indirectly influence this as, based on the outcomes, the quality of life of people with autism will be improved, with fewer restrictions of physical intervention. Equally, we will see improvements in the wellbeing of the workforce with a reduction in stress and burnout, which is a cause of sickness. This in turn will impact and reduce the cost and again create funding for other ventures.

1.4 Transferability of the PBS Framework to other Clinical Fields

The expectation of this research is that we will be able to transfer the findings of this study to other fields. It is also expected that this doctoral study will be able to influence the wider community of social and health care providers. To consider this, I referred back to my original community of practice identified in 1.2. It was important to refer back to this as the transference of this study meant growing my community of practice and careful consideration was required to ensure this was targeted to the appropriate clinical fields. It was also important to consider the questions outlined in 1.3 to ensure the integrity of my research would be relevant to other fields.

Another area to consider was who in the community could promote the profile of this research and help embed it into practice. The communities of practice identified were:

- Local authority healthcare commissioners.

  These professionals are in a position of power and have the ability to drive standards and improve practice through the development of contract service specifications. I have already been successful in working with commissioning teams in integrating the practice framework into contracts in some areas of the country, however, more is needed and further transferability to health authorities is required. PBS has a growing audience in healthcare; therefore, this is an obvious route to take.

- Dementia specialist services.

The PBS holistic framework has been designed so that the assessment processes and training components based on autism can be flexibly changed to include another specialisms. The principles of PBS can also be generically applied across all social care fields. The importance of environments, maintaining skills and promoting communication are equally relevant in dementia services. During this research, PBS was implemented in autism services where service users were also diagnosed with early onset dementia. Although not clinically trialled, there was an understanding among both social care and dementia specialists that PBS maintained the service users' provision longer than expected before the eventual move into a dementia service for palliative care.

- Children's and adults residential and educational settings.

  In the course of this study and my career I had begun to implement PBS into children's services where the specialism was autism. During Ofsted inspections, the inspection officer could see how elements of the practice framework would be beneficial in more generic children's services. My current role now oversees both children and adult care services for a wide range of disabilities across the UK, Wales and Northern Ireland; therefore this route seemed natural.

  Transition from child to adult services can be a difficult time for the young person; however, this would be significantly lessened by a seamless PBS pathway between the two services. Equally, broadening the PBS profile across Wales and Northern Ireland, where my organisation has new emergent services, will grow good leadership and practice within the community of practice from the onset.

1.5 Dissemination

In 1.4 I have identified the community of practice areas that this framework can be transferred to in order to improve PBS leadership and practice. Here I consider where this should be disseminated and presented. Again, this is an important area to consider and to ensure I am reaching the correct audiences for this type of research. I was also conscious that I wanted to target specific modes of dissemination rather than aiming at numerous types.

As PBS can be applied generically and be adapted to a multitude of clinical practices, a wider audience was considered for publishing my work. The *International Journal of Positive Behavioural Support* is a peer-reviewed publication. The publication aims were reviewed and were considered to be congruent with my research, in effect ensuring the integrity of my work. Below, I outline the journal's aims:

1. Define and promote good practice in relation to the use of PBS;
2. Add to the evidence base regarding such interventions;
3. Demonstrate how PBS interventions can support people to change their challenging

behaviours, improve their quality of life, result in reductions in the use of restrictive procedures (such as physical intervention, seclusion and medication), and bridge the gap between academic research and service practice.

The PBS International Leadership Conference was chosen because it is familiar and I am known at this conference following my commendation in 2014 for my PBS practice. This conference is well respected; it is organised by the British Institute for Learning Disabilities and professionals from all over the world attend. These conferences allow keynote speakers to present their work and facilitate workshops where their work can be disseminated and discussed in more detail with like-minded professionals. This will allow me to not only disseminate my work, but also to reach a broader network of the community for validation.

1.6 Conclusions

This chapter has provided an overview of the theory surrounding 'community of practice', as well as describing the relevance of profession and professional identity. The work of Lave and Wenger provided a theoretical overview of community of practice and assisted in providing an understanding of the domain, community and practice.

My contribution to and impact on practice has focused on closing the theory-practice gap with the development and implementation of a Holistic Positive Behaviour Practice Framework for Autism Practitioners and how this developed through academic research and practitioner experience. The researched also moved beyond the depth and breadth of what was researched and identified secondary outcomes such as reduction in high cost placements, reduced staff levels, improved practice capabilities and cross boundary partnerships etc. Transferability and dissemination considerations were discussed, outlining the rationale and thinking behind the decisions.

CHAPTER 2: AIMS OF THE RESEARCH

2.1 Introduction

Supporting people with autism is a highly skilled and complex profession and the complexities increase significantly when behaviours of concern are present. These behaviours are not only challenging for the person with autism, but are equally challenging for practitioners. According to evidence-based research, the impact of this is threefold:

1. When behaviour support strategies are functionally inconsistent with the person's needs, the outcomes include restrictive practices, increased behaviour and a reduction in quality of life (Carr, 2007).

2. Staff begin to react to behaviour rather than respond to the person's needs (Lovett, 1996) and the impact of this is staff burning out, a high turn-over and practices that are inconsistent with the person's person-centred needs and autism, which then can become restrictive.

3. Leaders of organisations are challenged in designing systems, e.g. practice frameworks, that are fit for the purpose of autism services and in developing the local capacity of skilled autism practitioners who can support people positively with their behaviours (Mansell, 2007, 2010).

Through the current research and experience of working at both an operational and strategic level, this thesis will provide a detailed account of the 'Holistic Positive Behaviour Support Training Framework for Autism Practitioners'.

This chapter introduces the current research and contextualises it within the community of autism practice in adult services. It considers the background and inspiration for the research and the significance of the study. It addresses the focus and aims of the research and presents the research questions. Finally, a description of the anticipated outcomes and the structure of the thesis conclude this chapter.

2.2 Background and Motivation of the Research

Over the past 25 years, I have worked in and managed many autism-specific services and experienced first-hand the challenges of supporting people with autism. Unfortunately, the harsh reality of these services often resulted in people with autism not having their needs met due to staff lacking the necessary knowledge, not only of autism, but also of how and why behaviour occurs. The impact of this on the person's quality of life would often lead to more behaviours of concern and a reduction in opportunity, choice and inclusion. I have had the pleasure of working alongside many committed and motivated colleagues; however, their health and social wellbeing is very often also affected, causing burnout, many injuries and

ultimately resulting in a high turnover. All of this directly impacts the wellbeing of people with autism and their behaviour.

Throughout my career, I continued to implement the same strategies that I had been shown by more 'experienced' colleagues, however, little changed. An incident occurred in 1992, which I call my 'happenstance moment': I was involved in an incident with a young man with autism and I was seriously injured. For most people that would have been enough to move on from this job, but for me it signalled a turning point; I realised that I needed to change. My knowledge needed to change.

I began my academic journey by applying my new learning to my practice and I started to see immediate results. I gained promotions and began using my new knowledge to mentor other members of staff. I started to develop my own theories and watched how in practice they improved people's lives, including my own. Unbeknown to me, I was already implementing the principles of a new evolution in behaviour practice – Positive Behaviour Support (PBS).

In 2002, another 'happenstance moment' occurred. During a regional management meeting I was asked to present my work to colleagues across the UK. In doing so, I met four other individuals who spoke about behaviour the way I did, which at the time was very rare. This was the conception of the first Positive Behaviour Support Team and over the next several years we developed training courses and a physical intervention model that ensured autism practice was embedded so that behaviours of concern would reduce.

In 2009, my colleagues and I were accredited with the British Institute for Learning Disabilities. There were only 24 accredited organisations in the UK. We were also the first organisation to become accredited that was also delivering direct services to people who challenge, rather than solely being a training provider. This led us and my work to be nationally recognised within the community of practice and opened doors to new networks.

The concept of this research evolved over the following years and although I remained interested in PBS, I also recognised the value of leadership and management in order to sustain a PBS approach. In 2005, I joined the world of academia again and enrolled on an Applied Management Degree. This opened up my world to new theories and practices and the Holistic Positive Behaviour Support Practice Framework for Autism Practitioners evolved. By the end of my degree, I was designing the framework and testing this out in practice whilst critically reflecting on findings. Practice was changing for the good because practitioners were being persuaded that this new way of working was valid.

The framework needed more academic testing, so I enrolled in an MSc in Applied Management where I was able to explore the leadership and management components necessary to underpin the framework. This helped me to contextualise my work and make professional sense of the phenomena.

In 2012, I was invited to take part in government discussions concerning the transformation of care as part of the UK national response to the Winterbourne View scandal. The

Department of Health published 'Transforming Care: a national response to Winterbourne View Hospital' (2012b) as a result of these discussions. In 2013, I was invited to attend a government review of the Autism Strategy as part of a wider network of autism providers. The Department of Health (2014), 'Think Autism Fulfilling and Rewarding Lives, the Strategy for Adults with Autism in England: an update' was developed following these discussions.

In 2014, the impact that the practice framework had on the lives of children and young people with autism received international recognition. A case study of a young man with autism was presented to the BILD PBS International Leadership Awards, where my work received international commendation for the impact it had on practice. Elements of my holistic practice framework were now being used by a number of national organisations and practitioners. The feedback I was receiving was positive and I became an advisor to various organisations. As a member of the autism community, I was often called upon to advise and offer guidance on Positive Behaviour Support.

2.3 Significance of the Research

Autism practitioners do some of the most difficult jobs: they work closely with people with autism who face significant challenges and express intense emotional reactions, and in this environment their patience, skills and personal strength are regularly tested. The weight of these responsibilities is heaviest when a person is most distraught and aggressive towards themself, others, and the environment, and if they cannot be calmed, staff must be prepared to intervene effectively and safely. Social care employers and practitioners are responsible for ensuring that they are prepared, through training, advice and supervision, to undertake this demanding work. Yet despite the level of responsibilities, there is a general absence of good practical guidance that interprets legislation and policy into practice standards. This lack of guidance is just one reason for developing a holistic PBS framework. By directly addressing positive behaviour strategies for people with autism, it emphasises the need for practitioners to have the right skills, knowledge and attitudes when supporting these people.

Placing emphasis on proactive strategies and working on a strength and person-centred approach will reduce the occasions when practitioners need to physically intervene, and will also prepare practitioners for the times when this is absolutely necessary. During the course of my career, the user voice has very much influenced this research, from both the viewpoint of autism practitioners and also through people with autism. Their evaluations of previous service delivery and service delivery after PBS has been embedded empowers their voice, allowing it to be captured and to contribute to this research.

This doctoral study will be the first of its kind, translating policy into a holistic practice framework specific to leaders and practitioners specialising in autism. This research will have an impact at the very front level of person-centred care. It will go further than the academic

perspective and place a lens over leadership, managerial and clinical practice whilst positively contributing to the lives of people with autism and their support staff.

2.4 The Focus and Aims of the Research

The aim of this research is to design, implement and embed a Positive Behaviour Support Practice Framework for Autism Practitioners across a national leading social care provider that provides services to people who also present with behaviours of concern. The research aims are threefold:

1. Core aim: reduce the use of restrictive practices and enhance the quality of life of both people with autism and support staff;

2. Develop and embed Leadership and Management Practice Standards that have been informed by evidence-based research and practice;

3. Contribute to the autism and PBS community of practice.

The focus and aims of the research are to evaluate existing standards within the community of practice and move beyond a point of evaluation in order to develop and identify new knowledge so that the gap between theory and practice is bridged. A degree of evaluation of these new standards will also be undertaken. This will promote the core aim and impact the very front level of person-centred care in autism services by enhancing quality of life and reducing restrictive physical intervention. Figure 1 captures this:

Figure 1: Focus of the Research

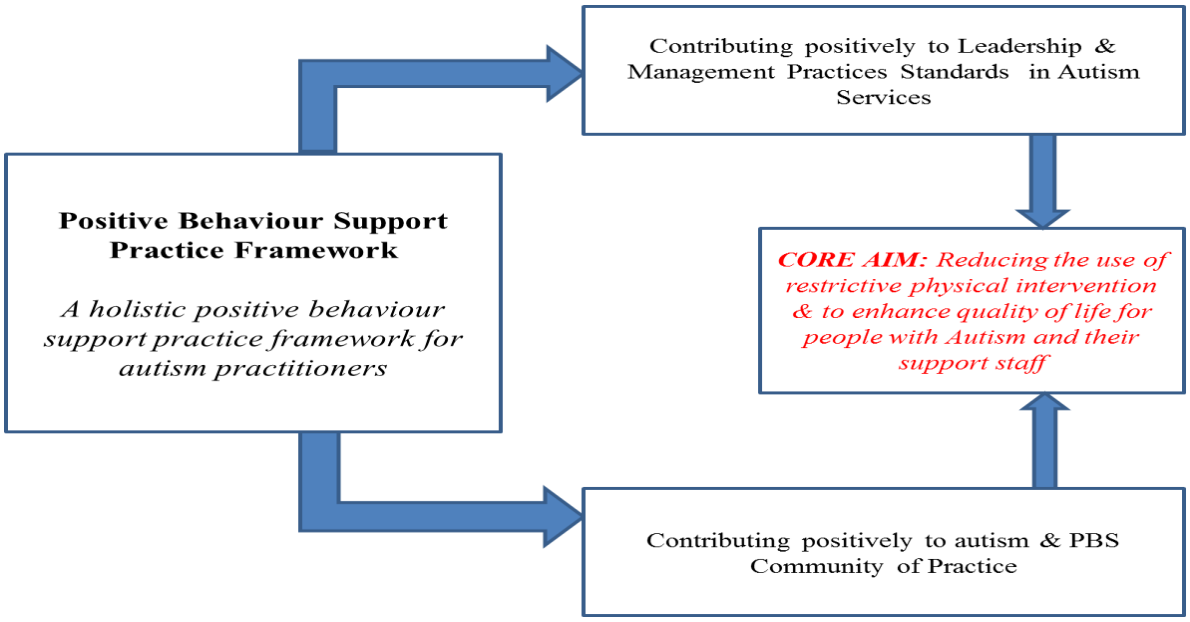


Figure 1 illustrates the research and looks beyond care, recognising that in order to sustain quality of life, a focus on restrictive practice reduction and leadership and management is also crucial for the durability of the PBS Framework.

2.5 Research Questions

An iterative process was applied to this research by reviewing the literature and undertaking a critical discussion, whilst also considering differing arguments, theories and approaches. The literature was synthesised with the research phenomena, which helped to identify the research questions. In order to add further rigour and structure to the literature, Bronfenbrenner's (1979) Ecology Systems Theory was used as an analytical tool to construct the research questions.

In Bronfenbrenner's seminal research he stated that human development is influenced by different types of environmental systems. Adopting this analytical tool helped to understand why the participants in the study behaved differently in their respective roles and how these interactions shape the current environment. Bronfenbrenner's theory defines complex stratums of the environment, each of which has an effect on the social care environment. This theory helped to illuminate research questions and was the rationale for choosing this theoretical approach.

2.5.1 The micro system

The micro setting is the direct environment we all experience in our lives. In this case, family, friends, work colleagues, managers and people with autism, all of whom have direct contact with the practitioner. The micro system is the setting in which we have direct social interactions with these social agents. The theory suggests that we are not just recipients of the experiences we have when socialising with each other in this environment, but we are also contributing to constructing the environment.

Within the career history of a social care practitioner, they will encounter various different environments, all of which will influence their behaviour. Bronfenbrenner argued that instability and unpredictability of an environment is created by the economic state in which the practitioner operates and is one of the most destructive forces in the development of practice. According to ecological theory, if the relationship in the immediate micro system breaks down, the practitioner will not have the tools to explore other parts of their environment.

The implications of this on adult social care and for people with autism are considered by many in the community to be dire. The community is already experiencing deficiencies in recruitment and from an educational perspective we are seeing fewer students undertaking health and social care, in particular learning disability nursing. Competency and capability are key attributes for the community and they are becoming increasingly problematic. Relationships with people with autism are formed based on these attributes and, without them, behaviours of concern become more apparent. Equally, societal attitudes have been

affected in recent years due to the Winterbourne View exposé. The role of the social care practitioner, managers and directors has been stained as a result and recruitment is made even more challenging by the fact that society currently holds a negative perception of care in general. The key micro research questions that will be focused on in this study are:

1. ***What are the key criteria practice standards in developing a PBS framework that will enhance the competencies and capabilities of autism practitioners so that autism practices are predictable and offer stability for people with autism?***

2. ***What are the quality of life outcomes from implementing a PBS practice framework for people with autism and the autism practitioners?***

2.5.2 The meso system

The meso system refers to the relationships between the micro systems in a practitioner's life; this highlights that the practitioner's career history may well influence their current role. For example, if the practitioner has had a negative experience in a job where there have been high levels of aggressive behaviour from a person with autism, he or she may have a low chance of developing a positive attitude towards managers, directors and people with autism now and in the future. Further, he or she may well consider aggressive behaviour as the norm in practice and focus on a person's behaviour, rather than improving quality of life, thereby following a more restrictive practice model.

There may also be greater resistance to changing attitudes and implementing up to date current thinking and practice standards if policies are not embedded, all of which contributes to an invisible and institutional culture within a meso system and will affect all other ecological systems. The connections between colleagues, professionals and people with autism consequently become disconnected, communication becomes distorted and the translation of policy into practice will no doubt affect values, attitudes and norms. Conversely, if the historical context has been positive, then productive relationships and effective communication will be evident. The research question posed here is:

3. ***How does organisational policy impact on autism and PBS practice; in particular how are values, attitudes and norms created when translating policy into practice?***

2.5.3 The exo system

The exo system is the setting that does not involve the practitioner as an active participant, but can still affect them. This may involve decision making where the practitioner has not been part of the process. In this research context, the government as an institution changed the statutory regulations as a result of Winterbourne View. Endorsing PBS as a practice model without appropriate design, implementation and integration could cause immense change to a practitioner's exo system when there has been no interaction with it. Changes to policies and practices without understanding the context can cause anxiety, confusion and an unwillingness to change subsequent practice. Conflict and relationship breakdown between the practitioner and leaders can occur, which can then influence the micro system of the

person with autism and cause behaviours. Communicating the government's message in an effective and responsive way will result in more understanding and ownership of policy and procedural changes, thus having a positive influence on the individuals' micro-system. The research question posed here is:

4. ***What are the practice benchmark indicators required in order to achieve UK statutory compliance in services and how can these positively influence the exo system?***

2.5.4 The macro system

The macro system refers to the culture and sub-cultures of the environment. This may include the economic position of social care, cultural values and the political sands that are shifting due to Winterbourne View and other revelations. This, like the other environments, can have a positive or negative effect on a practitioner's development. For example, where practitioners, managers and directors have worked in various organisations, they can bring a great deal of tacit knowledge, diverse perspectives and examples of best practice. They may, however, bring with them practices that are not up to date, more traditional and more restrictive because this is how they have learned how to practice. The current ideology of the PBS model could become distorted due to being influenced by these factors and the translation into practice may be affected. Conversely, practitioners who have been mentored through good leadership will be more susceptible and tolerant of change and be reflective within their practices, thus creating a transparent and open culture. An array of questions could be asked in this regard, however, this research will focus on:

5. ***How do the interactions and interconnectedness of different policy factors within a PBS context affect practice and what are the dynamics at play that can cause a 'lost in translation' phenomenon?***

6. ***What are the leadership and governance practices required to promote open and transparent cultures that can help to positively shape the economic and political environment?***

2.5.5 The chrono system

The chrono system includes the transitions and shifts in the practitioner's own lifespan. This may also involve the socio-historical contexts that influence them, such as career backgrounds. For this, I use the example of my research motivation as a 'happenstance moment' resulting in a passion to explore and develop PBS practices in autism services. This not only changed my relationship with people with autism and colleagues, but also influenced others' behaviours. Some colleagues were negatively affected by this due to their difficulties with change. Understanding social influences will help shape the value base of this framework. The research question posed here is:

7. ***To what extent do social care influences impact the community of practice?***

2.6 Research Aims and Questions Framework

Figure 2 provides a visual summary and synthesis of the Ecology Systems Theory Model, the questions associated with each of the systems and the data collection methods to be used to answer the questions.

Figure 2: Research Aims and Questions Framework

2.7 Anticipated Outcomes within the Community of Practice

As Director of Operations, I am in a leadership position nationally across the UK, Wales and Northern Ireland in Positive Behaviour Support and Autism Practice for a large charity that provides support to people with autism, learning disabilities and associated complex needs. I am therefore able to influence policy and practice at a senior level. The anticipated outcomes of this research will inform my community of practice at various levels:

- Leadership – this research will influence leaders by broadening their understanding of PBS at corporate level and reduce the likelihood of policy being lost in translation. Leaders will be informed about how to develop governance systems that are congruent with the PBS Framework, support robust monitoring of good practice and be more proactive when there are performance issues.

- Management – PBS standards that have been benchmarked against current research, thinking and practice will inform managers on a day to day basis of what good PBS practice looks like. Managers will become role models and will be the vehicles for dissemination of the framework in order to promote positive values and attitudes of the PBS philosophy.

- Workforce – the research will influence staff at the front level of practice. Services and teams will develop a cohesive workforce and through critical reflection they will promote competent clinical practice. Local authorities will equally benefit from this framework indirectly by developing the local capacity for existing and for future service provision.

- People with autism – a focus on the person rather than behaviour will develop. This will increase the level of confidence and self-determination and empower the person to develop their skills and independence. With the support of the practice standards, peoples' anxieties that lead to behaviours of concern will reduce and lives will be enhanced. The governance arrangements will also promote robust safeguarding and monitoring of any restrictive practice use and reduce the likelihood of aversive and abusive practices occurring.

2.8 Structure of the Thesis

The thesis reports the progress of the study towards the aims and outcomes outlined above. In the following chapter, the relevant literature in the areas of PBS and autism is described, evidencing how this has informed the research and design of the PBS Framework. The fourth chapter provides a comprehensive overview of the methodology, in particular the philosophical foundation, research design and methods used. In Chapters 5, 6 and 7 the PBS holistic framework is discussed, providing the evidence-based practice standards designed and influenced by the literature. The study findings are addressed according to the subsets of Ecology Systems Theory, which are then discussed with recommendations and conclusions.

2.9 Structure of the Doctoral Portfolio

In their discussion of the 'portfolio', Arter and Spandel (1992) note that it is:

> a purposeful collection of student work that tells the story of the student's efforts, progress, or achievement in a given area. This collection must include student participation in the selection of portfolio content; the guidelines for selection; the criteria for judging merit; and evidence of student self-reflection

A portfolio is a learning tool that helps to:

- Review and reflect upon my development and the research process;
- Organise my thoughts;
- Apply theory to practice and identify what has been lost in translation;
- Demonstrate my progress to others;
- Decide what new learning I have gained or still need.

Alongside Arter and Spandel's (1992) work, Maxwell and Kupczyk-Romanczuk (2009) also helped me to consider how to structure my portfolio. Borrowing the Greek temple metaphor used by Maxwell and Kupczyk-Romanczuk, the portfolio became the foundation of my research, the pillars represented the themes (PBS practice standards) of the framework and the report became the roof. All of this embraced the current thinking and practice of the phenomena, whilst also utilising emergent new knowledge. The structure of the portfolio has therefore been designed into a set of nine practice standards (the pillars), alongside a toolkit of practice templates and learning and development training workshops. Each of the nine standards responds directly to the current literature and findings within the study. This should be read in conjunction with this thesis.

2.10 Learning Outcomes of the Doctoral Programme

During the course of the professional doctorate, a student is expected to achieve certain learning outcomes in order to demonstrate the following knowledge (see Table 1):

Table 1: Professional Doctorate Knowledge Outcomes

K1	Deep understanding of the recent developments in their profession, both nationally and internationally.
K2	Deep understanding of current theoretical frameworks and approaches that have direct relevance to their own professional context.

Alongside these knowledge outcomes, students are also required to demonstrate the following skills and abilities (see Table 2):

Table 2: Professional Doctorate Skills and Abilities

S1	Make a significant contribution within their chosen field.
S2	Apply theory and research methodology within the workplace, and feel comfortable in integrating different approaches to address "messy" multi-disciplinary problems in a rigorous yet practical manner.
S3	Recognise budgetary, political, strategic, ethical and social issues when addressing issues within the workplace.
S4	Reflect on their work, and on themselves and thus operate as a truly reflective independent practitioner.
S5	Present and defend an original and coherent body of work that demonstrates, reflects upon and evaluates the impact upon practice that they have personally made.

The clarity of both the report and the portfolio is essential so that readers can be navigated through the information, whilst also being told explicitly how the knowledge, skills and attributes have been achieved. In order to achieve this, the cross-referenced Table 3 captures how these learning outcomes have been met:

Table 3: Professional Doctorate Learning Outcomes

	Learning Outcomes	How Achieved	Report Sec./Ch.	Portfolio Standard/ Sec.
K1	Deep understanding of the recent developments in their profession nationally and internationally.	Exploration into understanding my Community of Practice and my Professional Identity.	Ch.1/2.2	
		First direct provider of services to become accredited nationally in 2009.	2.2	
		Evolution of Positive Behaviour Support.	Ch.3/3.2	Intro
		Relevant key institutes, e.g. WHO, NICHE, NAS explored according to current research and thinking.	3.6	Intro
		UK National context brings together current organizational, leadership and practice challenges.	3.9 & 3.10	Intro
		Invited to take part in Government discussions.	Ch.2/2.2 Ch.3/3.7	

		International context explored and draws on similarities to UK context.	3.8	1-9
		Policy and practice context explored what has been lost in translation.	3.10	2
		Governance explored the practitioner and organizational factors.	3.12 Ch.4/4.2 Ch.6/6.3	1/7/10
		Training and capable workforce development.	3.13 Ch6/6.6	1-10
K2	Deep understanding of current theoretical frameworks and approaches, which have direct relevance to their own professional context.	Bronfenbrenner's Ecology Systems Theory (1979)	Ch.2	1-10
		Review of relevant literature on Positive Behaviour Support and Autism.	Ch.3	2:2-11
		UK national legislative context is drawn upon to develop Practice Standard 2.		
		Ethical & Value led Theoretical Perspectives, Decision Making Grid & Training	Ch.3/3.15	1-10
		Leadership & Management Theoretical Perspectives	Ch.3/3.20	1-2
		Epistemological and Ontological perspectives	Ch.4/4.2	
		Situational Analysis (Clarke, 2005)	Ch.4/4.4	1-10
S1	Make a significant contribution within their chosen field.	Commendation at British Institute for Learning Disabilities, PBS International Leadership Awards for Innovative PBS work for Children & Young People (2014).	Ch2/2.2	1-10
		First direct provider of services to be nationally accredited.	2.2	
		Invited in discussions with the UK Government and contributed to the publication of Department of Health *Transforming Care: a national response to Winterbourne View Hospital* (2012b).	2.2/ Ch.3/3.7	
		Invited and contributed to Department of Health (2014), *Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update*.	2.2/ Ch.3/3.7 Ch.5 Ch.6-7	

S2	Apply theory and research methodology within the workplace, and feel comfortable in integrating different approaches to address "messy" multi-disciplinary problems in a rigorous yet practical manner.	Bronfenbrenner (1979) Ecology Systems Theory Epistemological & Ontological Perspective Researcher Positionality & Embedded Stance Situational Analysis (Clarke, 2005) - Situational Mapping - Social Worlds/Arena Maps - Positional Maps - Discourse Analysis - Reflexivity Mixed method approach using semi structured interviews, focus groups and questionnaires.	Ch. 2,5,6& 7 Ch.4/4.2 4.2.4 Ch.4/4.4 Ch.4/4.5	1-10
S3	Recognize budgetary, political, strategic, ethical and social issues when addressing issues within the workplace.	Bronfenbrenner (1979) Ecology Systems Theory Epidemiology of Autism in UK & Consequences of Autism Cost of Autism in UK Universal Preventions Policy Translation Ecology Systems	Ch.2/2.5 Ch.5/6/7 Ch.3/3.3 & 3.4 3.7 3.8 3.12 Ch.5/6/7	1-10
S4	Reflect on their work, and on themselves, and thus operate as a truly reflective independent practitioner.	Motivation for study Reflexivity	Ch.2/2.2 Ch.4/4.4.5 Ch.5/6/7	1-10 7-8
S5	Present and defend an original and coherent body of work, which demonstrates, reflects upon, and evaluates the impact upon practice, which they have personally made.	Holistic Positive Behaviour Support Practice Framework for Autism Practitioners.	Ch.5 Ch.6 Ch.7	1-10

Table 3 provides readers of this doctoral study with an overview of the innovative approach that has been used to achieve the final evidence within the portfolio. The following chapter presents the first step in achieving this.

2.11 Conclusions

This chapter began by introducing my motivation for the study. I discuss my own experience of supporting and managing autism services and the challenges that professionals face in such a complex situation. Meeting other like-minded professionals and creating a learning arena

was the first real step forward in developing a PBS community of practice. Over the coming years, my professional identity grew and became internationally recognised.

The significance of the research is addressed above, noting the lack of good practice standards as policy does not go far enough. The research addresses translating policy into practice standards and will have an impact at the front of person-centred care, going further than an academic perspective by placing the lens on leadership and management practice.

It is noted that the focus of the research is in designing, implementing and integrating a PBS practice framework into autism services and the core aims and questions were structured by synthesising this with Ecology Systems Theory. The anticipated outcomes identify how leaders, managers, practitioners and people with autism are influenced by the framework. The structure of the thesis and portfolio is outlined to offer easy navigation for the reader, and the learning outcomes, skills and abilities are outlined and cross referenced with the portfolio/framework.

CHAPTER 3: LITERATURE REVIEW

3.1 Introduction

Continuing on from the research questions outlined in Chapter 2, this chapter reviews the relevant literature in order to outline the situation for the research. Reviewing relevant policy, articles, professional journals and academic papers enables a critical review of the state of the profession. Appendix A offers further clarification on the literature search.

To provide the background to this study, the first part of this chapter discusses the history of autism and the epidemiology of the condition in the UK. The consequences of autism are highlighted and the pressure on services to support people exhibiting behaviours of concern is discussed from a practice and research perspective. The cost of supporting people with autism illuminates the reality for the economy today. A synthesis of ecology systems theory and an exploration of universal approaches to prevention, particularly of integrating policy and practice, are considered. The main body of the literature review concentrates on autism and behaviours of concern within the national and international policy context. It focuses on the triangulation of policy, which informs the components necessary for a PBS practice framework.

This chapter addresses what has been 'lost in translation' as policy is converted into practice, and particularly the impact this has on the community of practice and the lives of people living with autism and their support staff. The literature review critically evaluates the evolution of PBS, its principles and quality of life outcomes. Alongside this, the importance of practice leadership and management is critiqued against relevant theoretical perspectives.

To conclude, this chapter reports on how the literature has informed governance and the training of a capable workforce and the components required in practitioner training to promote PBS practice within the context of an autism specific service.

3.2 History of Autism

Autism is not a new phenomenon; it can be traced as far back as 1797 to a French physician, Jean-Marc-Gaspard Itard, who discovered a young boy living wild in the woods who exhibited several autistic traits and became known as the Wild Boy of Avalon. Itard treated the boy with a behavioural program that consisted of developing social attachments and speech and language therapy.

Paul Eugen Bleuler, a Swiss psychiatrist, is thought to be the first person to use the term 'autism' in 1910; he derived the term from the Greek word 'autos', meaning 'self'. Autism got its modern name in 1938 when Hans Asperger, an Austrian paediatrician, first described a group of individuals who shared common traits as 'autistic psychopaths'. In 1944, he published the first definition of Asperger's syndrome, identifying patterns of behaviour: lack of empathy, little ability to form friendships, one sided conversations and restricted interests.

In 1943, Leo Kanner first used the term autism in its modern sense in English when he introduced the label ‘early infantile autism’ in a report on 11 children with striking behavioural similarities. Almost all the characteristics described in Kanner’s first paper on the subject, notably “autistic aloneness” and “insistence on sameness”, are still regarded as typical of the autistic spectrum of condition today.

Rutter (1978) extended Kanner’s theory and suggested three criteria for defining childhood autism. These were:

- Impaired social development that has a number of special characteristics out of keeping with the child's intellectual level;
- Delayed and deviant language development that also has certain defined features and is out of keeping with the child's intellectual level;
- Insistence on sameness', as shown by stereotyped play patterns, abnormal preoccupations or resistance to change resulting in aggressive behaviours.

Denckla (1986) published the deliberations of a workshop on the diagnosis of autism and related disorders. The participants agreed that the essential features of autism were:

- Social impairment;
- Delayed or deviant language (communication);
- Repetitive, stereotyped or ritualistic behaviour.

These were considered the familiar features appearing in all definitions. The difference was the recognition, in agreement with Wing and Gould (1979), that all these features could occur in widely varying degrees of severity and in many different manifestations.

From the 1960s through to the 1970s, research into treatments for autism focused on medications such as LSD, electric shock and behavioural change techniques. The latter relied on pain and punishment. In the 1960s, an American psychologist and parent of a child with autism, Bernard Rimland (1964), wrote a landmark text, *Infantile Autism: the Syndrome and its Implications for a Neural Theory of Behavior*, suggesting that autism was a neurological disorder – based in biology, not faulty relationships. At the same time, professional thinking around the formation of, and interventions for, mental, cognitive and emotional disorders was changing and behaviourism moved its focus from early relationships to learned behaviours. If individuals had learned inappropriate or unhelpful behaviours, they could be helped to learn more adaptive behaviours. Through the 1970s and 1980s, behavioural study continued and the work of Ivar Lovaas, whilst controversial at the time and since then, was influential in demonstrating that people with autism could learn more normative behaviours (Anderson, 2007).

Autism thereby came to be seen as a neurological condition that was treatable by psychological intervention. Many of the earlier observations were forgotten: Kanner had remarked on the increased head size of children with autism; Asperger had noted similar personality traits in the parents of children with Asperger’s syndrome (Wolff, 2004). Whilst

some of the strategies used over this period are now anathema to professionals, this phase in the evolution of our understanding of autism recognised that children are able to learn and to develop. During the 1980s and 1990s, the role of behavioural therapy continued and the use of highly controlled learning environments emerged as the primary treatment for many forms of autism and related conditions. Currently, the cornerstones of autism therapy are behavioural therapy and language therapy.

Work through the 1980s and 1990s framed autism as a developmental disorder: affected children did not reach developmental milestones in the areas of language, socialisation and imagination/flexibility of thought and behaviour. Toward the end of the 1990s, it became increasingly recognised that people on the spectrum also experienced high rates of anxiety and marked sensory-perceptual differences, resulting in a number of important texts dealing with these aspects of the condition (Seroussi, 2002).

Today, according to the World Health Organization (WHO, 2013):

> Autistic Spectrum Disorder' (ASD) is an 'umbrella' term which covers a range of conditions such as Autism, Asperger Syndrome, Childhood Disintegrative Disorder and Pathologic Demand Avoidance (PDA). Autism is a lifelong, developmental condition that affects the way a person communicates, interacts, processes information and may present with a restricted, stereotyped repetitive repertoire of activities and interests.

The condition can vary from person to person, as well as throughout individuals' lives, and some may have a decreased intellectual ability. Individuals on the autism spectrum often have other conditions; this can include, but is not restricted to: epilepsy, metabolic disorders such as phenylketonuria, sensory impairments and genetic conditions such as fragile X syndrome and Down's syndrome (Boucher, 2011).

The National Institute for Health and Care Excellence (NIHCE, 2013) describes autism as:

> Qualitative differences and impairments in reciprocal social interaction and communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact. In addition to these features, people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems. These can include a need for routine and difficulty understanding other people, including their intentions, feelings and perspectives.

The clinical picture of autism is variable because of differences in the severity of autism itself, the presence of coexisting conditions and the differing levels of cognitive ability, which can range from profound intellectual disability in some people, to average or above average intellectual ability in others. It is recognised that this population represent a complex and vulnerable group in society and are susceptible to stigma and discrimination.

3.3 Epidemiology of Autism in the UK

The National Autistic Society cites that around 700,000 people have autism in the UK, which equates to more than 1 in 100 in the population. 'Autism Spectrum Disorders in Adults Living in Households throughout England' (Brugha et al., 2007) notes that 4.5% of males has an autistic spectrum condition, as opposed to 0.3% of females. According to the Foundation for People with Learning Disabilities, approximately 60-70% of these people also have an intellectual disability (IQ below 70), as opposed to a global prevalence to be 1 in 160 people, accounting for more than 7.6 million with the condition (WHO, 2013).

Emerson and Baines (2007) estimated that between 20% and 33% of adults known to councils who have learning disabilities also have autism. Across England, this suggests that between 35,000 and 58,000 adults who are likely users of social care services have both learning disabilities and autism. The number of adults in the population who actually have both learning disabilities and autism (including those who do not use specialised social care services) is likely to be much higher.

Emerson and Baines' research was carried forwarded by the Department of Health (2012), whose published report – Estimating the Prevalence of Autistic Spectrum Conditions in Adults – stated that the prevalence of autism is known to increase according to the severity of the learning disability, thereby increasing the likelihood of autism and severe forms of behaviour. 70% of people with autism in the UK also meet the diagnostic criteria for at least one other unrecognised difficulty, such as self-injurious behaviour, anxiety and aggressive behaviours.

3.4 Consequences of Autism

Although many people with high functioning autism can live independently in our communities, those with co-morbid intellectual disabilities often require a lifetime of specialist support (Matson and Shoemaker, 2009). Complexities of autism are further pressurised due to people reporting more mental health problems, aggressive behaviours and stress within families (Totsika, Hastings, Emerson, Lancaster and Berridge, 2011). The consequence of this is a predictor for psychotropic medication and hospital admission.

It is well researched that individuals with autism exhibit higher levels of challenging behaviour than those with intellectual disabilities (Ando and Yoshimura, 1979a; Bhaumik, Branford, McGrother and Thorp, 1997; Bradley et al., 2004; McClintock, Hall and Oliver, 2003). As a result of these behaviours, people with autism are more likely to endure more restrictive practices such as control and restraint.

3.5 Autism and Behaviours of Concern

Understanding the core domains of autism and how this can impact on the person and their individual needs is key to understanding what they are trying to communicate. As a result of

these core domains, people may frequently become frustrated, stressed or aggressive. Applying this understanding is essential if we are to see beyond the behaviour of a person.

For the purpose of clarity, the contemporary phrase 'behaviours of concern' relates to the more traditional phrase of 'challenging behaviours'. The working definition from Emerson's (2001) seminal research in 'Challenging Behaviour: analysis and intervention in people with learning disabilities' provides researchers and practitioners with a commonly used definition:

> Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.

This definition was updated by the Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists in the Unified Approach (2007) to demonstrate how behaviour can impact on quality of life:

> Behaviour of such intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.

The core domains of autism can impact on a person's life and lead to feelings of frustration, confusion, anxiety or lack of control, resulting in behaviours that challenge both the person themselves and their support staff. Since behaviour is often a form of communication, many individuals with autism voice their wants, needs or concerns through behaviours, rather than words.

In a study by Wilkinson (2013), 'Aggression and Autism Spectrum Disorders', it is estimated that as many as 70% to 84% of people on the spectrum will have co-occurring problems often exacerbated by the core symptoms of ASD and this can lead to significant functional impairment. Among these problems, physical aggression appears to be especially challenging and has been associated with serious negative outcomes in both the general population and among individuals with ASD and other developmental disabilities.

Self-injurious behaviour also appears to be relevant to the occurrence of aggression (Emerson, 1992). Individuals with ASD are at an increased risk of demonstrating self-injurious behaviours, as compared to those without ASD, with prevalence rates ranging from 30% to 53% (Richards et al., 2012). Although self-injury and other forms of challenging behaviours have been considered distinct forms of behaviour, they are often related. For example, physical aggression and self-injury have been significantly associated among individuals with severe intellectual impairment, as well as autism, and there is evidence that self-injurious behaviours are precursors of later aggression in this population.

In response to a study by Emerson et al. (2011), Chowdhury and Benson (2012) identified the outcomes of such behaviour when interventions have not succeeded. Health and wellbeing is often poor and even life threatening, opportunities are restricted and often deprived and a

more reactive approach and focus on the behaviour is practiced. Reporting on a range of studies, Emerson (2003) found that personal risk factors (e.g. severe intellectual impairment, communication difficulties and autism) increased the likelihood of living in residential care with high staffing levels and restrictive practices. Further risk factors found by McGill et al. (2009) indicated that males with autism were more likely to be subject to restrictive practices.

3.6 Autism and Restrictive Physical Interventions

Autism and the use of physical interventions have only recently come under systematic scrutiny and this is the last amongst the wide range of interventions to be subjected to rigorous examination. Questions continue to be raised by the community of practice regarding the risk factors associated with restraint, not to mention the emotional and psychological damage its use can have on the person.

In Paterson et al.'s (1998) seminal research they concluded that in the UK, restraint tended to be 'physical'. This involved the restriction of movement by holding a person physically, as opposed to other countries that predominantly use 'mechanical' means, i.e. where a device is used to restrict movement. UK care staff, as in many other countries, were increasingly being trained in control and restraint measures to prevent violence and further aggression in an attempt to improve the safety of people with autism and support staff.

Further research over the following years has concluded that restraint is still not risk free, with serious injuries reported to both the person with autism and staff, including UK-reported deaths from restraint. However, there has been little research into acceptable practice of restraint and more often studies focus on a particular aspect of the person's death rather than examining in depth the wider implications of such deaths for policy and practice.

The Department of Health 'Positive and Proactive Care: reducing the need for restrictive interventions' (2014) recently attempted to offer clarity on the use of restrictive physical interventions, which people with autism may experience:

- Physical Intervention refers to 'any direct physical contact where the intervener's intention is to prevent, restrict, or subdue movement of the body, or part of the body of another person'.
- Mechanical Restraint refers to 'the use of a device to prevent, restrict or subdue movement of a person's body, or part of body, for the primary purpose of behavioural control'.
- Chemical Restraint refers to 'the use of medication which is prescribed, and administered for the purpose of controlling or subduing disturbed/violent behaviour, where it is not prescribed for the treatment of a formally identified physical or mental illness'.
- Seclusion refers to 'the supervised confinement and isolation of a person, away from other users of services, in an area from which the person is prevented from leaving. Its

sole aim is the containment of severely disturbed behaviour, which is likely to cause harm to others'.

The prevalence of restrictive practice towards people with autism is as high as 50% (Emerson, 2003). In later studies, this was confirmed in a survey of NHS, local authority, third sector and private residential services. Deveau and McGill (2009) found that almost half of respondents reported using some form of restrictive practice and a third reported using physical interventions that are more restrictive. Joint research with the Challenging Behaviour Foundation (Allen, Hawkins and Cooper, 2006) found that 87.5% of family carers had used physical interventions with their relative and over 20% used them on a frequent basis.

The limited research undertaken over the last 20 years in this area all concludes with a reminder that restraint is intrinsically an unsafe procedure, which, however, in some circumstances may be less dangerous than the alternatives available. The most obvious way of reducing the risk of restraint-related deaths is to avoid restraint in the first place by actively promoting alternative intervention and management strategies that focus on primary and secondary prevention, such as PBS.

3.7 Cost of Autism in the UK

The cost of supporting a person with autism who presents with aggressive behaviour can be considerable and the more behaviours increase, the greater the costs to the economic system. A study by Knapp, Romeo and Beecham (2007), 'The Economic Consequences of Autism in the UK', outlined its financial cost to the UK economy. For adults, the research focused on the autistic spectrum between low and high functioning and considered the costs of lost employment for both the person with autism and their parents. The following estimations were developed:

- An adult with high functioning autism living in a private household costs £32,681 per annum;
- For an adult with high functioning autism living in supported accommodation or a care home, costs increased (£84,703 and £87,299 respectively);
- Adults with low functioning autism were found to be £36,507 for those living in private households, £87,652 in supported accommodation, £88,937 in residential care, and £97,863 in hospital. Individuals in residential care and hospital tended to be people with behaviours of concern.

The aggregate national cost of supporting a child with autism was estimated to be £2.7 billion each year with most costs accounted for by services. For adults, the aggregate costs amounted to £25 billion each year. Of this total, 59% was accounted for by services, 36% by lost employment for the individual with autism, and the rest by family expenses. The life cost (including education and housing) for an individual with low functioning autism was £4.7 million in the UK. However, the deficits in the dimensions associated with autism, in

particular behaviour, often outweigh positive outcomes and the cost of service provision can be significantly higher (Howlin et al., 2004b).

Given the significant clinical and financial implications, clinically relevant research that can impact on the lives of individuals with autism and those caring for them is well overdue and warranted, but is currently inadequate in research terms.

3.8 Universal Approaches to Prevention

The focus on physical interventions, which has mainly been due to deaths by restraint in recent years, has allowed the community to consider how we can improve this difficult but necessary action. This difficulty is reinforced by an increasingly litigious culture with an overemphasis on risk management and health and safety. Ironically, this heavily funded field lacks evidence base, preventative approaches and, even with strong research findings, it had no legislative drivers until the publication of 'DH Positive and Proactive Care' (2014). Little has changed in resourcing the PBS approach and consequently it is infrequently applied in the community.

The literature has demonstrated that we frequently practise approaches for which there is no evidence base and we rarely practise those for which there is an evidence base. People with autism have a history of being excluded; in an age in which evidence-based practice is meant to be the norm for all, they are effectively being excluded yet again.

Until the Department of Health 2014 publication, adopting a preventative approach did not have any clear guidance. By synthesising the work of Bronfenbrenner (1979), 'Ecology Systems Theory', prevention can only be achieved by considering the interface of a wide variety of variables, although it is not just about staff training and governance as this publication suggests. Considering Bronfenbrenner's systems theory, these have been divided into the following broad systems to illuminate this point:

- Socio-historical Level (Chrono System) – How to support a person presenting with aggressive behaviours is often influenced at the operational level by the social care influences in society and our own historical experiences. In today's society we often use buzzwords such as 'zero tolerance'; these have been formed in debates on violence management in settings such as hospitals where behaviour is attributed to internal controllable causes where people can do something about their behaviour if they wish. However, transferring such descriptions to an autism setting is less effective and meaningless to these individuals due to disability. Aggression here is more accurately attributed to external uncontrollable causes such as the person's frustration with receiving insufficient support to communicate or complete a task.

  The relationship between wider societal views and the organisation therefore becomes bi-directional, and how a service supports its users will in turn impact on how society views the individuals concerned.

- Leadership and Governance (Macro System) – Organisations who set out their strategic vision, direction and intent will play a clear role in determining how violence and aggression is addressed. Cultures and sub-cultures should create a level of transparency, however; if the organisation chooses to ignore this issue, then so will its employees. If the organisation chooses to invest in reactive approaches to aggression, then the result will be heightened levels of reactive responses as the predominant approach. Organisations that sign up to a therapeutic approach such as PBS develop clear policies and positive approaches to training their workforces in behaviour, and they have a reflective practice embedded in quality assurance systems.

- Quality of Life Outcomes (Micro System) – Management are tasked with the responsibility of promoting and implementing the vision. This will involve quality of life indicators for both the person with autism and staff. Being an organisation that is person-centred promotes respect, empowerment and independence. Effective supervision systems based on direct observation of staff performance can promote competence. Management and staff interactions create positive influences by offering regular and constructive feedback. Workforce cohesiveness creates further confidence and opportunities for both the person with autism and staff, which promotes confidence and motivation.

3.9 PBS National Policy Context

In 1981 the British public saw the ITV documentary entitled *The Silent Minority*, which exposed abuse experienced by vulnerable patients in long stay hospitals, many of whom had a diagnosis of autism and learning disabilities. There were many shocking scenes publicised; some of the worst showing a young person being tied to a pillar and older adults locked in cages to control behaviour. This documentary was considered controversial and an 'unrepresented' exposé of people in long stay hospitals. It led to questions in parliament and the Secretary of State for Social Services gave assurances that there would be improvements and more person-centred care provided.

Further exposés were later televised, such as the BBC undercover Macintyre investigation in 1999 about a Kent care home for people with learning disabilities and autism. The documentary identified five separate assaults in just 21 days of filming and inappropriate and disproportionate use of physical interventions. The Human Rights Act 1998, which also applies to Wales and Scotland, was already giving consideration to restrictive practices, e.g. use of physical intervention via mechanical, chemical or environmental methods, and subsequent training needed to include this.

Government policy changed as a result of the Macintyre documentary, with the introduction of the Department of Education and Skills and Department of Health guidance (2002) for the social and health care communities. The Guidance for Restrictive Physical Interventions, 'How to Provide Safe Services for People with Learning Disabilities and Autistic Spectrum

Disorder', was influential in raising standards in practice. It focused on the importance of policy frameworks, together with appropriate behaviour support and training for staff.

In response to the need to clarify standards relating to training in physical interventions, the British Institute for Learning Disabilities (BILD) published its first edition of the BILD code of Practice (2001). This code provided a voluntary framework for trainers and commissioners in physical intervention training. The primary aim of the code was to set common standards against which to measure training. The application of the code provided standards on:

- Training to emphasise proactive and preventative approaches;
- Development of policy frameworks in services;
- The balancing of rights and responsibilities of service users and staff;
- Raising awareness of relevant legislation, e.g. Human Rights Act;
- Providing a structured framework of training content and frequency of training.

Alongside the code, BILD established the Physical Intervention Accreditation Scheme and the criterion for membership was, and still is, based on the successful implementation of the code of practice. The Welsh Assembly published the 'Framework for Physical Intervention Policy and Practice 2007', which also focused on a framework for the use of restrictive practices, as did The Healthcare Commission in Northern Ireland in their guidance 'Equal Lives: review of policy and services for people with a learning disability 2005'.

In the following years, despite much being improved about vulnerable people's lives in long stay hospitals, stories of shocking abuse continued to emerge. 'Valuing People – A New Strategy for Learning Disability for the 21st Century' was the government white paper published in March 2001 by the Department of Health. This was the first white paper on learning disability for 30 years and it set out an ambitious and challenging programme of action for improving services. The four key principles of "rights, independence, choice and inclusion" lay at the heart of the government's proposals. Legislation which confers rights on all citizens, including the Human Rights Act 1998 and the Disability Discrimination Act 1995, applied equally to people with learning disabilities, and the Disability Rights Commission would work for people with learning disabilities.

In 2001, the Welsh Assembly also published 'Fulfilling the Promises – Proposals for a Framework for Services for People with Learning Disabilities', which focused on the prevention of challenging behaviours and providing people with behaviour action plans that were functionally appropriate. The assembly reported that in Wales, 12% to 17% of people with learning disabilities and/or autism showed challenging behaviour and of those, 40% to 60% showed more severe challenging behaviour. This was largely due to services lacking the capability to meet these people's complex needs. They advocated more specialist support services within community-based settings and developing and increasing expertise across the community of practice in both health and social care.

In 2009, the government, aware of widespread criticism that 'Valuing People' had 'lost impetus' published 'Valuing People Now: a new three-year strategy for people with learning

disabilities'. 'Valuing People Now' brought the 2001 'Valuing People' white paper up to date and addressed recent changes in government policy, including the personalisation of social care. The vision set out that all people with learning disabilities, including autism, should be supported to become empowered citizens. For the first time, the government identified that those with 'complex needs' must not be excluded and should be considered to be the most vulnerable in our society.

In the strategy, the term 'complex needs' was used to describe a range of multiple and additional needs that people with learning disabilities may have. This included people with profound learning disabilities and people whose behaviour presents a challenge. This strategy also alluded to (although it was not explicit in its language) a PBS philosophy. It identified that behaviours that seem challenging are simply part of a person's disability; it is known that these behaviours serve a function for the individual and it is essential to identify what that function is. The strategy acknowledged that behaviours are the only way that individuals have of communicating that their needs are not being met and it is essential to address them to avoid further risks to quality of life.

The Mansell report commissioned by the Department of Health, 'Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs 2007', offered more momentum to services that supported people with complex needs. This publication came after the closure of long stay hospitals shown in *The Silent Minority* and it was commissioned by the Secretary of State for Care Services in order to evaluate progress since 'Valuing People 2001' for people with learning disabilities, autism and mental health.

The primary goal of this report was to drive up standards of practice, offering guidance to local authorities and service providers on providing sufficiently skilled support staff so as to be more proactive in their support and management of people with behaviours of concern. Mansell identified that good progress had been made since the publication of 'Valuing People'; however, progress for people with challenging behaviour had lagged behind. Mansell went further, stating there had been a failure to develop appropriate services, which had led to placement breakdown and vulnerable people being placed in expensive provisions away from their home and community. The essence of the report suggested that councils should not be reactive; instead, they should strengthen their commissioning to integrate expertise about challenging behaviour, alongside developing services to be ready and fit for purpose when needed.

The Mansell report was the first publication to provide further guidance on how the local capability in the workforce should be addressed and the type of training required. He contextualised the challenges faced by providers, who often increase staffing levels at greater cost to local authorities in order to manage challenging behaviour. Instead, he advised that commissioners should fund more skilled expert training in order to educate the workforce, which would then sustain more capability. He advocated that understanding the causes of challenging behaviour to prevent it escalating would be far more effective than skilling staff to manage reactively.

By this point, there had been a substantial growth in training staff in physical intervention, which then resulted in greater increase in physical intervention and rights being abused. No training in the reasons why behaviour occurs and how to be proactive in managing this would often lead to staff using the last resort of physical intervention as a first resort when prevention was possible. The impact of this on quality of life directly affected the 'Valuing People' key principles of "rights, independence, choice and inclusion". Although this publication was widely accepted across the community as 'good practice', however, it was not statutorily endorsed.

In 2007, Mansell was also commissioned by the Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, and he published 'Challenging Behaviour: a Unified Approach – Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices', which was considered an influential publication in integrating multidisciplinary and multiple agencies to focus on those who are vulnerable to restrictive interventions and abuse. The unifying principle of this report was the need to improve the quality of life of people whose behaviours challenge services, whilst also guiding and contributing to research and development. This report is still very much alive, active and responsive in terms of generating national debate and evaluation of good practice and it has been incorporated into both legislation and further national guidance. It continues to be a key driver in both policy and practice, although it still omits informing the community of 'how' to implement this in practice.

One of Mansell's last publications before his untimely death was 'Raising our Sights: services for adults with profound intellectual and multiple disabilities 2010'. This report had a central message about major obstacles to the wider implementation of policy for adults with profound intellectual disabilities due to prejudice, discrimination and low expectations. He reinforced the message of quality of life through more a person-centred approach and specialised care and support through assessment of needs and personalising vulnerable people's care packages. He criticised the government for not having enough skilled and trained staff to provide self-directed support to vulnerable people. The impact of this led to further breakdowns in support, and an increase in vulnerable people having their rights deprived and being placed in residential care.

More recently, the use and risks of restrictive practices towards people with autism and learning disabilities has received much attention. These methods of control against vulnerable people are commonplace in many UK and international services (Allen, 2011). The UK has seen a number of high profile investigations in relation to the management of people with autism, intellectual disabilities and mental health. These include Cornwall (Healthcare Commission, 2006), Sutton and Merton (Healthcare Commission, 2007), and the BBC *Undercover Care: the abuse exposed* (2011) in relation to vulnerable people in Winterbourne View Hospital.

These scandals exposed poor practices towards vulnerable people and, as a result of the national outcry that followed, in England there was an increased focus from the government

on models of care, inspection, standards of practice and regulation. Underpinning guidance across the nation was developed and consultation and cross-functional partnership working commenced with health and social care professionals, commissioners and service providers. Key national reports, such as the Department of Health 'Winterbourne View Review Concordat: programme of action' (2012a) and the Department of Health, 'Transforming Care: a national response to Winterbourne View Hospital (2012b), provided the impetus for further change in the management of behaviours of concern. A review between academics and health and social care professionals brought thinking up to date within the field, in particular noting the increasing importance of positive behaviour support approaches.

The outcome of this was that the Department of Health published new statutory guidance, 'Positive and Proactive Care: reducing the need for restrictive interventions 2014', in England that aimed to minimise the use of restrictive practices and promote positive behaviour support as the model of practice in the management of behaviours of concern. From April 2014, the DH launched a new, wider two-year initiative called Positive and Safe to deliver the transformation of care across all health and adult social care. The identification of levers to bring about these changes included improving reporting, training and governance. The government embarked on a large-scale system-wide change initiative ensuring more contemporary, compassionate and therapeutic approaches to supporting people with behaviours of concern.

Skills for Care and Skills for Health, in partnership with Positive and Proactive Care, published 'A Positive and Proactive Workforce: a guide to workforce development for commissioners and employers seeking to minimise the use of restrictive practices in social care and health 2014'. This provided the community of practice with a framework to radically transform culture, leadership and professional practice. Its aim was to deliver care and support, to keep people safe and promote recovery. The guide offered support and guidance to commissioners and employers so that they could develop a workforce that was skilled, knowledgeable, competent and well supported to work positively and proactively using positive behaviour support approaches. It focused on key areas of practice that are unpinned ethically and legally by the European Convention of Human Rights.

'Think Autism Fulfilling and Rewarding Lives: the strategy for adults with autism in England: an update' (2014) was issued in response to its first publication in 2010. The new Think Autism strategy placed the spotlight on some key areas for improvement:

- Autism awareness training for all staff;
- Provide specialist autism training for key staff, such as GPs and community care assessors to promote autism friendly environments;
- Cannot refuse a community care assessment for adults with autism based solely on IQ;
- Local authorities must appoint an autism leader in their area;
- Local authorities must develop a clear pathway to diagnosis and assessment for adults with autism (National Autistic Society, 2015).

These areas of improvement have been strengthened by the new Care Act (2016), which places new statutory responsibilities upon local authorities to implement improvements in the quality of life for people with autism and to endorse and practice a positive behaviour model.

More recently, the National Institute for Health and Clinical Excellence (NIHCE) published their response to the changing face of health and social care for people whose behaviours challenge services. 'Challenging Behaviour and Learning Disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges' (2015) provides an in-depth acknowledgement of positive behaviour support. It goes further than the other publications by providing standards on behaviour assessment (e.g. functional behaviour assessments) and the quality of positive behaviour support planning, although it falls short of providing a whole systems guidance approach. Commissioners of services have endorsed this guidance, which encapsulates all of the current research and literature to date; however, little evidence has been seen in services.

New legislation, such as the Mental Capacity Act (2005) and Deprivation of Liberty Safeguards (2007), the Autism Act (2009), Health and Social Care Act (2015) and the Care Act (2016), have all been acknowledged and embedded into statutory and non-statutory guidance. The regulatory body for the sector, the Care Quality Commission (CQC) have come under fire in recent years for their lack of a robust and transparent inspection framework. This was particularly attributed to Winterbourne View, where CQC failed to follow up on safeguarding notifications, either with the management of Winterbourne View or with the police and social services. On other occasions, CQC failed to monitor the hospital's progress against performance action plans in response to problems identified in regulatory inspections.

In April 2015, CQC introduced a new inspection framework that sets out five 'domains', assessing providers on whether they are:

1. Safe;
2. Effective;
3. Caring;
4. Responsive to people's needs;
5. Well-led

Leadership and management has been strengthened as a result of the serious case reviews and the CQC will assess service providers, local health and social care authorities using five key lines of enquiry: the enacted organisational vision and strategy; the governance arrangements; the organisation's leadership and culture; how providers engage, seek and act on feedback; and the extent to which the provider seeks to continuously learn and improve. Significantly, these five lines of enquiry cover the leadership and culture of a provider. The impact of this is yet to be seen, however, these new lines of enquiry have been welcomed by the community of practice. The UK social and health care political environment is more united now than it has ever been in supporting people who challenge.

3.10 PBS International Policy Context

Australia has been a leading authority alongside the UK in developing PBS across its social and health care system. The Department of Human Services in the Victoria State Government published the positive practice framework: A Guide to Positive Behaviour Services Practitioners (2011). This publication is only a practice reference resource; however, it is widespread across the state, reflecting the government's commitment to promoting contemporary service delivery for people with disabilities. The primary aim of this framework is to enhance quality of life and minimise behaviours of concern. The principles of the framework are congruent with the statutory regulations within the Disability Services Act (2006).

The framework, like the UK policy context, brings together contemporary research and thinking so that PBS practitioners can present a clear practice model whilst integrating their knowledge and skills within the practice setting. In order to support the translation of this framework into practice, the Victoria State Government developed the Behaviour Support Services Practice Advisory Group, which supports services in developing and sustaining effective practice and positive outcomes for people with a disability.

The Disability Services Act is explicit in its understanding of positive behaviour support and it promotes the PBS principles. An example of this can be found in the Act's definition of positive behaviour support plans:

> a plan developed for a person with a disability which specifies a range of strategies to be used in managing the person's behaviour including proactive strategies to build on the person's strengths and increase their life skills.

Principles of positive behaviour support are entrenched in the Charter of Human Rights and Responsibilities (2006) and Australia became a signatory of the Convention of the Rights of Persons with a Disability by the United Nations in 2008, whilst the UK followed a year later. The Convention of Rights is designed to protect the rights and dignity of disabled people and is often drawn upon in research to challenge the use of restrictive practices.

The Office of the Senior Practitioner (Department of Human Services, 2009, 2010) developed a sophisticated monitoring database, which was backed by the Disability Act. This is now employed on a state-wide basis to monitor behaviour plans that involve any use of restrictive practice. As this is a recent initiative, outcome data is not yet available on the efficacy of the programme. This is a policy (and practice) area that is currently lacking in the UK and it has been left to the interpretation of providers. There is no central data captured to identify the state of the situation and no policy drivers to promote this. This seriously jeopardises the rights of people with autism and without the global situation being fully understood, it will only be considered in micro terms at local silo levels.

Australia has witnessed a 'paradigm shift' in the attitudes and approaches within the sector, with greater emphasis being placed on practices such as restraint reduction, increasing

people's rights to decision making and becoming active and valued citizens within their communities. The Disabilities Service Commission published the 'Positive Behaviour Framework' (2014), which cited West Australian Sector Health Check (SHC) on the Disability Services and concluded, "challenging behaviour is a human rights and quality of life issue for people with disabilities and their families." Like Mansell, in 2007 the SHC identified that there was a "limited capacity of the sector as a whole" in terms of skilled and knowledgeable PBS practitioners. The impact of this included:

- High cost in provision;
- People who were challenged not having their needs met, which therefore increases their behaviour further;
- Access to the most appropriate and specialised provision being far away from the person's home.

The SHC provided a number of recommendations and was commissioned to lead and facilitate engagement across the sector in the planning, development and implementation of a comprehensive and consistent, evidence-based approach to better respond to the needs of people with disabilities who exhibit challenging behaviour. The current scope of their work is on services supporting people with autism and learning disabilities. As a result of this work 'A Framework for Recognition and Management of Challenging Behaviour' (2013) was published, which sets out a framework for action and was intended to inform future strategic planning for the disability sector. The actions centred on improvements in coordination and provision of specialist behaviour provision and skilled practitioners.

Similarly, the United States Congress reviewed and amended the Individuals with Disabilities Education Act (IDEA, 1997), where positive behavioural support has held a unique place in special education law. PBIS, referred to as Positive Behavioral Interventions and Supports in IDEA, is the only approach to addressing behaviour that is specifically mentioned in the law within the US. This is the only country that currently cites PBS in legislation. This emphasis on using functional assessment and positive approaches to encourage good behaviour remained in the Act when it was further amended in 2004. Congress further recognised that, in order to encourage implementation of PBIS, funds need to be allocated to training in the use of PBIS. Thus, IDEA provided additional support for the use of PBIS in its provisions by authorising states to use professional development funds to provide training in methods of positive behaviour interventions to improve people's behaviour.

In a publication a year earlier from the Child Welfare League of America, Bullard et al. (2003) identified leadership, organisational culture, person-centred approaches, agency policies, staff training, treatment environment and continuous quality improvement as the critical components to reducing restrictive practices in children's disability services. This report stressed the importance of individualised and functionally appropriate positive behaviour plans with a primary focus on prevention and behaviour reduction. Colton (2004, 2008) synthesised the major themes within Bullard et al.'s work by developing a checklist for assessing an organisation's readiness for reducing seclusion and restraint in learning

disability services. This covered nine themes, all of which were relevant to a PBS whole systems approach:

- Leadership;
- Orientation;
- Training;
- Staffing;
- Environmental factors;
- Programmatic structure;
- Timely and responsive treatment planning;
- Debriefing;
- Communication and consumer involvement;
- Systems evaluation and quality improvement.

Allen (2011) reviewed this work and identified eight characteristics for successful reduction initiatives:

- Effective leadership;
- Changes in policy;
- Changes in philosophy;
- Individualised assessments;
- User participation;
- Commitment across the organisations;
- Systematic data reviews.

This tool was intended to be used as a way of capturing gaps in regulation and operational performance, capturing change across the organisation and assessing cultural change in practices.

3.11 Triangulation of Policy Context

Although there is a lack of robust research in PBS, especially for people with autism, there is significant policy-based evidence that is producing some common themes. Analysis of the key policy ingredients suggests that it is possible to identify critical strategic and practice areas for a PBS framework. In summary these are:

- Leadership;
- Person-centred planning;
- Local policy development;
- Holistic assessment;
- Creating capable environments;
- Data driven practice and quality assurance;
- Workforce practice development;
- Post incident management systems;

- Underpinning all of the above – ethics.

3.12 The Lost Translation of PBS Policy

Research and evidence-based practice has shown us over the past few decades that the interpretation of behaviour policy as practice has resulted in the abuse of vulnerable people. Understanding the reasons for this and exploring the gaps between rhetoric and reality will help draw out the inconsistencies and difficulties of implementing PBS policy within complex need organisations.

The term 'lost in translation' is used and defined for the purpose of this thesis as: leaders of complex needs organisations develop positive behaviour support policies and interpret these into localised policies and practices, and some details of the original meaning is not present, resulting in:

- Losing the essence of the message;
- Inconsistencies in application of PBS practice;
- Mischaracterisation of PBS;
- Gaps between leadership and clinical practice;
- Miscommunication of the message to the workforce.

In recent years, we have seen in the media that the 'PBS lost in translation phenomenon' can have a powerful negative effect on people with autism and this often leads to more intensive behaviours and restriction. The secondary impact of this places significant pressures on the social care system with service breakdowns, staff injury and burnout, along with increased hospital admissions and increased costs to the economy (Mansell, 2007, 2010).

The literature demonstrates that over the past two to three years there has been a renewed attempt to clarify and tackle policy, practice and other influences; however, appraising the literature and drawing on comparisons from the serious case reviews over the past several years, the categories outlined below go some way to explaining how this translational phenomenon can occur.

3.12.1 Philosophy and practice of PBS

In a study by LaVigna and Willis (2012), they argue that there are organisations across national and international waters that publically state they are implementing a PBS model and have embedded this philosophy and practice in their policies. In their research, 'The Efficacy of Positive Behavioural Support with the Most Challenging Behaviour: the evidence and its implications', they found a number of organisations who did not practice the use of functional behaviour assessments, measure baseline behaviours or periodically review the PBS plan. LaVigna and Willis go further in their argument by stating that if practice does not demonstrate and measure the minimisation of negative outcomes in people's lives, then this cannot be a PBS model of practice.

In many cases, local policies have adopted some of the philosophies and practices of PBS; however, at the fundamental core of a PBS model is quality of life through functional behaviour assessments, which are known to reduce behaviours of concern and through periodically reviewing the person's plan this will demonstrate and quantify behaviour reduction. Consequently, in the absence of this, what is being practices is not PBS. There is a danger here that PBS is then diluted further and causes a mischaracterisation of the model and clinical practice then becomes inconsistent.

3.12.2 Environmental accommodation

The Mansell (2007) report recommended that people with complex behaviours are best suited to environments where their needs are compatible with others. Mansell acknowledged, however, that the term 'compatible', in reality meant "behaviours that are compatible". Thus, people with behaviours of concern tend to live with others who have equally complex behaviours. The result of this in reality is that more intense behaviours occur due to the environments in which people are placed. A focus is then placed more on behaviour than the functions of behaviour and not on exploring quality of life improvements. Behaviour incidents in these environments are more frequent due to the unpredictability of each person's needs. In their research, 'A Literature Review on Multiple and Complex Needs' (2007) the Scottish Executive stated that planning does not meet or address the housing needs of these vulnerable people and in effect creates more behaviour and complexities within the social care system. In the more recent research, 'Use of Positive Behaviour Support to Tackle Challenging Behaviour', Allen and Baker (2012) confirm that the UK is still faced with the difficulty of locating suitable accommodation and greater costs to society in both monetary and social terms.

3.12.3 Regulation of training

Currently, there is no regulation of training providers who deliver courses on PBS or physical intervention. National reports have recognised the present unregulated market economy of training provision and the poor quality of the research literature has meant that commissioners of restraint training are often heavily influenced by the marketing activities of commercial training companies that are unsupported by valid research evidence in their effectiveness (Deveau and McGill, 2007). This may suggest that training is even more risky. This in turn has led to an element of discourse and the debate focusing too much on 'whether system X is better than system Y', or whether 'technique A or B should be banned'.

In the absence of mandatory regulation, BILD developed the Accreditation Scheme, which is based on the BILD Code of Practice (2014). This is one of the few regulatory systems for training in the UK that has been endorsed by most local authority commissioners. In most local authority service contracts for autism and complex needs services, commissioners expect providers to deliver a physical intervention-training model that is BILD accredited. This does not identify a 'holistic' approach to understanding behaviour and currently local policy and practice still demonstrates a reactive and behaviour-focused approach to service delivery. This is largely due to litigation and increased safeguarding challenges.

Even though there has been a renewed effort to improve policy and practice, there is still no enthusiasm for mandatory regulation. As a result there is an unknown quantity of trainers who are practicing in the UK; they come from a range of backgrounds, but predominantly from a security background that is unregulated and there is no central register of who they are. The essence of the PBS message is therefore significantly lost in translation to the workforce and is fundamentally and ethically inconsistent with the value-led approach of PBS. Without an effective and properly funded, multi-sectoral scheme, we are clearly some years away from improving this and more research is needed.

3.12.4 Corporate governance

The case at Winterbourne View demonstrated to the community of practice that the workforce had indeed been trained in a BILD accredited training model. This highlighted that training is only one piece of the puzzle. Leaders and managers at Winterbourne View were not skilled in PBS and had not developed a robust monitoring system that was congruent with protecting and supporting people with complex needs. The lack of a governance system therefore increases the interference of unskilled and dominant characters within a team, infecting policy into practice and the impact of this causes unimaginable distress to vulnerable people.

3.13 Evolution of PBS – A Critical Evaluation

Positive behaviour support (PBS) is an evidence-based approach to enhancing quality of life and reducing behaviours that can have a negative impact on the individual's preferred lifestyle. The emergence of positive behaviour support (PBS) has presented some challenges and opportunities in the community of practice. Many practitioners from an applied behaviour analysis (ABA) background believe that PBS poses a threat and is less effective. PBS is considered a branch of applied behaviour analysis and it still uses components of ABA within its practice. Some researchers consider PBS to be an extension to ABA (Dunlap, 2006). PBS is very much in its formative stage and as a result of this many perspectives and even misunderstandings are being formed by practitioners. The critical evaluation presented here will therefore aim to identify and explore these multiple perspectives. However, it will first consider the evolution of PBS.

PBS emerged in the mid-1980s and was considered an alternative to the dominant behaviour management practices that emphasised the manipulation of consequences to produce behaviour change, known as applied behaviour analysis. This practice had become the norm, causing an over-reliance on contingency management strategies that led to the use of highly aversive and stigmatising punishment-based procedures. The application of these aversive interventions was almost always seen among individuals with severe learning disabilities and/or autism and was regularly practiced in community residential-based settings. PBS emerged from this controversy.

A seminal article by Horner et al. (1990) began with the following statement, "In recent years, a broad-based movement has emerged in support of non-aversive behaviour management". Horner et al. emphasised that "Non-aversive behaviour management has developed as an alternative to the use of more extreme aversive events" and they created the phrase "positive behavior support". The authors went further with their claims, stating that "many people are being subjected to dehumanising interventions that are neither ethical nor beneficial", citing sources that contained strong statements of opinion but little objective data to support that assertion.

The first UK guidance that alluded to PBS, 'Challenging Behaviour: unified approach – Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices' (2007), stated that a PBS framework should be ethically valid and psychologically informed by functional assessments. Using applied science (e.g. ABA) that uses educational methods to expand the person's opportunities and independence through redesigning environments will create systems change that is durable in enhancing quality of life.

Despite ABA having a broad empirical foundation, PBS offered limited empirical research, thus causing confusion over its methodology and application. Horner et al. were tentative in their response. "There is no specific technique that distinguishes the approach. Different proponents offer varying procedural recommendations and different theories of behaviour in its support".

Horner et al. (2000) typified PBS as: "An approach that blends values about the rights of people with disabilities with a practical science about how learning and behavior change occur". In 2002, Carr et al. provided an updated definition of positive behaviour support:

> PBS is an applied science that uses educational methods to expand an individual's behaviour repertoire and systems change methods to redesign an individual's living environment to first enhance the individual's quality of life and, second, to minimize his or her problem behaviour.

Horner et al. continued to defend PBS, stating that there was too little information available to suggest that PBS is capable of solving all behaviour problems, or documenting that one approach is superior to any other. They advocated well controlled empirical analyses and less controlled clinical analyses.

During this timeframe, Horner et al. (2000) attempted to set parameters of PBS, which encompassed many of the ABA practices. In many respects this only added to the confusion and debate that continues to this day. ABA and PBS will always be inextricably linked and without clarification and further research this will continue to cause confusion in practice.

Carr (2007) tried to emphasise the centrality of PBS by adapting positive and supportive environments for the promotion of positive behaviour:

> Our chief concern is not with problem behaviour, and certainly not with problem people, but rather with problem contexts. Our job is to redesign the counter-productive and unfair environmental context that so many people, with and without disabilities, have to contend with in their everyday lives.

At this time, the policy situation in the UK was clearly emphasising and focusing on the behaviour of an individual; however, Carr (2007) was highlighting the role of the context in which the individual lives and the essential influences of environmental design. Behaviours of concern, as Carr alluded to, are socially constructed, an outcome of the person–environment interaction. Therefore, such behaviours are a 'challenge' to service systems and providers where the environment is not fit for need.

Moreover, research was producing evidence-based literature that behaviours of concern were often a reaction to inappropriate environments due to a lack of person-centred communication methods, a lack of autonomy, stimulation (over or under) and frustration. This research, however, did not come from a PBS-specific source and focused specifically on the ABA approach. As PBS is cited as a new applied science or discipline, as some have argued (e.g. Carr et al., 2002), it is reasonable to expect the publication of research questions, methods, findings etc. Currently there is difficulty in identifying research that is clearly and uniquely PBS in character.

PBS has continued to be an energetic and innovative practice over the years despite criticism. Over this time, PBS has expanded its applications across a wide range of countries and populations (Lucyshyn, Dunlap and Freeman, 2015), including people with autism and complex needs. The definition of PBS has been inconsistent due to its migration into different specialisms, however, Kincaid et al. (2015) have proposed a revised definition of PBS to the US Association of Positive Behaviour Support:

> PBS is an approach to behaviour support that includes an on-going process of research-based assessment, intervention, and data-based decision making focused on building social and other functional competencies, creating supportive contexts, and preventing the occurrence of problem behaviours.
>
> PBS relies on strategies that are respectful of a person's dignity and overall well-being and that are drawn primarily from behavioural, educational, and social sciences, although other evidence-based procedures may be incorporated. PBS may be applied within a multi-tiered framework at the level of the individual and at the level of larger systems.

This definition still demonstrates a flexible engagement of scientific procedures. Sailor and Paul (2004) stated that, "PBS thus departs from the traditional modern perspective on research in order to (a) inform professional practice by subduing methods of science applications in natural social contexts and (b) address problems from the standpoint of the individual affected. They further stated that, "Where ABA has historically been almost wholly focused on interventions that can be evaluated with positivist methods (i.e., single-

subject designs). PBS increasingly is relying on multi-method investigations that sometimes include subjectivist methodologies". Subjective, reflective opinions, impressions and beliefs therefore do not offer scientific rigor for the industry to examine or test due to the influence of many variables. The credibility and reliability of evidence is now discounted and reinforces the community's views of PBS being untested and not credible.

To reiterate an important point, however, PBS is in its early developmental stages. There is a consensus that PBS and ABA should remain closely linked until such time that PBS is further understood. Both PBS and ABA don't claim that they are the only behavioural model, however, they do agree that service delivery may require alternative approaches to varying contexts. PBS should be considered as a new approach rather than a new science of providing behavioural interventions that is grounded in the existing science of behaviour analysis.

3.14 Principles of PBS

The PBS model provides value and ethics-led principles, which are the backbone of any PBS practice framework. These values are well known in the field of learning disabilities and have long been accepted by diverse professions serving this population, including ABA. The following principles complement current policy; they were adapted by the seminal research of Carr et al. (2002) and continue to be a presence today:

- Enhancing quality of life through comprehensive lifestyle change: to support people in improving their holistic needs, e.g. social relationships, leisure opportunities, community integration, self-determination etc.;
- Examines the person's life and not just the behaviour: a lifespan perspective recognises that achieving sustained behaviour reduction will take years;
- Proactive and person-centred functional assessment: apply behavioural science in real life community settings and analyse the function of the unmet need through person-centred approaches;
- Multicomponent intervention: there is a recognition that there are multiple functions and structural variables that influence behaviour and will require a multi-dimensional strategic approach;
- Reduces behaviours of concern over time: applying the least restrictive alternative as short term strategies only to prevent serious harm to self, others or the destruction of property;
- Collaboration and stakeholder participation: stakeholders are active participants in the PBS model and are integral in defining quality of life whilst planning, assessing and designing intervention strategies;
- Systems change: focus on problem contexts, not problem behaviours, through system change that enables change to occur and be sustained; adopt a common vision, clear direction, adequate resources and training and incentives to change;
- Emphasis on prevention: development of proactive skill-building to support systems change;

- Flexibility of science practice: develop systematic data sources to evaluate and guide intervention;
- Social validity: define success by its objective effectiveness, practicality, desirability, contextual fit and subjective effectiveness (quality of life and behaviours of concern).

Within the PBS community, however, these values are part of the origin and definition of its approach to behavioural services (e.g. Anderson and Freeman, 2000; Carr et al., 2002; Horner, 1990). This priority seems to risk allowing values to serve as a filter through which research findings and effective treatment alternatives must pass. Such an emphasis can encourage clinical decision making to be guided more by cultural values than by research findings.

Philosophically, PBS subscribes to the early principles of normalisation which simply note that people with learning disabilities should be able to live in the same social settings as anyone else and be able to access the same opportunities as others. A fundamental component of normalisation is that it has social role valorisation at its core. This ensures that people who are at risk of being devalued and disadvantaged are supported to assume a valued social role within their community. This phenomenon led to the 'inclusion movement', which also prohibited the use of painful and restrictive practices and promoted skill-building through new person-centred strategies (Lucyshyn et al., 2015).

The empirical-based evidence for the claims noted above was less convincing than that of the ABA community. These broad claims appeared as a cheerleading exercise rather than concrete evidence-based literature; however, in many ways this only confirms Horner's claims that further research is required. ABA, on the other hand, boasts a dossier of evidence-based research in the movements of deinstitutionalisation and institutional reform (Burg, Reid and Lattimore, 1979; Scheerenberger, 1981), normalisation (Blatt and Kaplan, 1974; Wolfensberger, 1973), client rights and protections (Stolz, 1977) and person-centred planning (Osborne, 2005), to name a few.

3.15 What is an Ethical and Person-centred Value Framework?

Much has been made in the literature of ethics and value-led approaches being central to a PBS framework. This requires further explanation. Currently, the emphasis of decision making in social care is evidence-based practice, with a generally accepted assumption that this provides beneficial outcomes for people with autism. Rather than seeing evidence and values as separate aspects of decision making, values are central to the way one sees the world and decision making. The place of values in social care decision making, however, is not always acknowledged or understood.

Woodbridge and Fulford (2004) developed what they call the counterpart to evidence-based medicine, which we can draw comparisons from. Values-based medicine (VBM) is a 'fact and values model' of reasoning, which proposes that values and evidence are "the two feet on which all decisions in health (and any other context) stand". Seedhouse (2005b) adopts a

similar philosophical stance in his theory, concerned with exposing the values that drive and inform decision making. "All decisions are a balance of evidence and values. Obviously we should regard values as at least equally important as evidence. And yet we don't". Seedhouse takes his argument further, stating that evidence is visible while values are often neither visible, recognisable nor transparent (Seedhouse, 2009). People with autism have much greater access to information these days and more options for treatment and services, therefore the practitioner is no longer the only expert. This has led to a more democratic acceptance of people's individual rights, which we have seen in the literature, such as 'Valuing People' (2009) and 'Fulfilling and Rewarding Lives' (2010).

Seedhouse (2005) has also given considerable attention to practical philosophy in health care ethics. He argues that the aim of philosophy is "to improve our lives by bringing about increased clarity of understanding". Despite his claims in 2009 of a lack of transparency, Seedhouse strongly asserts that all aspects of health care, whether it be policy, planning or practice, is influenced by values.

Another important element to Seedhouse's philosophy is that all decisions, in all aspects of our lives, have an ethical component. He advocates an "everyday ethics" whereby alternative courses of action can be considered for any situation. Every decision will impact to some degree on others. Ethical dilemmas and moral conflicts are therefore an everyday reality in modern social care practice. In 2009, Seedhouse argued that ethics can be seen as pivotal in issues concerning:

- Consent;
- Privacy and confidentiality;
- Resource and treatment allocation;
- Rights and interests;
- Duties and obligations.

The ethical issues that are drawn on in the discussion in 3.14 can equally be applied to Seedhouse's pivotal issues, as Table 4 highlights:

Table 4: A Synthesis of the Ethical Grid (Seedhouse, 2009) and PBS Ethical Principles

Seedhouse Ethical Grid	PBS Ethical Principles
Serve needs first	▪ Enhancing quality of life ▪ Person-centred assessment of needs
Respect autonomy	▪ Supporting people to improve their holistic needs, relationships, leisure, community integration, self-determination
Create autonomy	▪ Self determination
Respect persons equally	▪ Holistic person-centred assessments ▪ Flexibility in practice

Minimise harm	▪ Do no harm ▪ Reduce and only adopt least restrictive practices ▪ Adapt environments
Tell the truth	▪ Truth is objective through assessment and multi collaboration
Keep promises	▪ Systems change creates common vision and purpose
Do most positive	▪ General Social Care Council ▪ Proactive and person-centred assessment ▪ Emphasis on prevention
Most beneficial outcome for individuals	▪ Restrictive practice reduction ▪ Systems change ▪ Enhanced quality of life
Most beneficial outcome for oneself/group	▪ Skill building through multi collaborative working ▪ Reflective practitioner
Most beneficial outcome for society	▪ Evidence-based data sources to evaluate and guide intervention and future needs ▪ Desirability of approach
Legal rights	▪ Reducing behaviours of restriction ▪ Least restrictive measures
Codes of practice	▪ General Social Care Council
Risk	▪ Least restrictive reduces risks
Effectiveness and efficiency of action	▪ Holistic assessments to understand person and know what is most effective/efficient ▪ Social validity and contextual fit
Resources available	▪ Effective and efficient resources are assessed as contextually fit to person
Wishes of others	▪ Collaboration of stakeholders in planning/assessing/monitoring/measuring
Disputed evidence/facts	▪ Data sources, factual evidence reduces disputes
Degree of certainty of the evidence on which action is taken	▪ Skill building and systematic measuring

Seedhouse also presents an overview of what he describes as ethical myths, which at present are a barrier to ethical reasoning. I have thus applied these to social care:

- Ethics is confined to leadership and management roles and practitioners see little importance in this;
- Ethics is concerned only with 'tip of the iceberg' issues and lacks depth and history;
- Ethics is considered resolvable by recourse to rules or laws.

Ethics requires us to pose the question: how do we make everyday decisions in our autism and PBS practice? Rather than being a formulaic guide to practice, ethics is about process. By examining a range of considerations and possible outcomes, it is therefore possible to raise an opinion to a well-reasoned argument with the rationale fully justified through thorough and thoughtful deliberation. Rather than being restricted to ethics experts or committees, ethical decision making can be undertaken by everyone involved in the delivery of autism and PBS practice.

There is a dearth of empirical studies identifying the factors involved in ethical decision making in practice. Alongside Seedhouse, however, a number of other studies are relevant to autism and the PBS community; these are outlined in Table 5:

Table 5: Empirical Studies on Ethical Decision Making

Four Quadrants' (or 'Four Topics'), Jonsen et al. (2010)	A four-box grid listing questions for each of the four topics: 1. Medical indications: diagnosis and treatment options 2. Person's preferences: patient values 3. Quality of life: aim is to improve this contextual feature – wider context, e.g. person's family, hospital policy, the law, heath system etc.
'Ethox Approach', UK Clinical Ethics Network	A flow chart and worksheet: ▪ Clinical/other facts relevant to the case? ▪ Appropriate decision-making process? (who, when, what are the procedural rules?) ▪ Morally significant features of each option (consider person's preferences, capacity, best interests, consequences) ▪ What does the law say? ▪ Moral arguments regarding each option ▪ Choose an option ▪ Evaluate your argument: can it be

	rebuffed? ▪ Make recommendation ▪ Review recommendation and learn from it

The Ethox approach offers more insight into the decision making process itself and particularly who, when and what the procedural rules are. This component from Seedhouse's Ethical Grid was adopted within the Holistic Framework.

The idea of everyday ethics has been developed further, giving rise to the notion of an ethics toolkit (Seedhouse, 2009). Considering this notion in terms of the practice framework, the 'toolkit', as Seedhouse has termed it, can contain values, rules and theories in order to support a practitioner, manager or leader's capacity and ability to reason and make decisions. Any training that follows this can help familiarise the community with the framework and develop transparency of ethics and values.

3.16 Person-centred Philosophy – A Critique

The community of practice that shaped the earliest approaches to person-centred philosophy did so between 1973 and about 1987 and comprised people from across North America. These professionals shared a passion for understanding and teaching how the principle of normalisation might be applied to improve the quality of services to people with developmental disabilities.

This community of practice provided the notion of person-centred approaches based on the close observation of how services affect people's lives. This led to a forum for debating difficult questions, formulating ideas grounded in their experience, inventing new ways to explore the experiences of people with intellectual disabilities, and a medium for communicating new ideas and approaches. Person-centred planning reflects a wide interpretation of what person-centred planning is. One definition of person-centred approaches is that they are:

> Ways of commissioning, providing and organising services rooted in listening to what people want to help them live in their communities as they choose. People are not simply placed in pre-existing services and expected to adjust, rather the service strives to adjust to the person. Person centred approaches look to mainstream services and community resources for assistance and do not limit themselves to what is available within specialist services. (Valuing People – A New Strategy for Learning Disability for the 21st Century, 2001)

The ideological underpinnings of person-centred approaches, as with PBS, are the following: people should be treated as individuals and individuals should enjoy better lives. Person-centred planning is about equality (Stalker and Campbell, 1998). There is some ideology that

is not explicit in this regard, however. For example, individuals should have ordinary yet meaningful lives (Wolfensberger, Thomas and Caruso, 1996) and the role of a service is to support this to happen; families and the wider personal unpaid network should be involved, including having a lead role; inclusion in mainstream resources; and an emphasis on assets rather than deficits. This does, however, challenge the unequal power structures that have long reigned in the relationships between service providers and service users. I would suggest that a change in thinking about power relations is fundamental; organisations need to operate from a position where they have 'power with' service users rather than 'power over' them.

In recent years, person-centred philosophy has been extended and it is now considered as person-centred active support. This is currently regarded as an important element in determining the quality of life of people with intellectual disabilities (Mansell, 2010 and Beadle-Brown et al, 2012), and in particular in increasing people's participation in daily life, social and community activities as well as increasing people's skills, adaptive behaviour and choice (McGill and Toogood, 1994; Jones et al., 2013; Beadle-Brown et al., 2014). Research spanning many years also indicates that person-centred active support should be a vital component in the support of people with challenging behaviour (McGill and Toogood, 1994; Jones et al., 2013). In order to ensure the successful implementation of this approach, good practice leadership is required at all levels within the organisation and this should be embedded in robust policy, procedures and training programmes.

As a philosophy that espouses notions of choice, independence and inclusion, ideas embedded in the concept of person-centred planning inevitably influence the way that services should be designed. As with Mansell (2007, 2010), this philosophy believes that rather than service users fitting into an existing universal service – a 'one size fits all' design – services should be designed to fit around the needs of individuals. By necessity, this implies that services need to be adaptable and able to evolve with the changing and dynamic needs of those who use them.

In a report published by the Joseph Rowntree Foundation in 2006, the authors cited numerous difficulties for social care staff in promoting such ideologies as being risk averse due to existing in a litigious society, resulting in restrictive measures being enforced on people's lives, not enough choice in provision due to the economic state of the community and practitioners not having the time to practice person-centeredness due to time being cut to support people. Traditional models of service delivery tend to base provision around the perceived needs of many, rather than the agreed needs of individuals. Magito-McLaughlin et al. (2002) state that compliance with regulations and the establishment of broad systems that impose rigorous standards of care have taken priority over attainment of individually desired outcomes or inclusion. This demonstrates a lack of progress in the community with barriers to self-determination that lie in threats to life, direct and indirect discrimination, and lack of entitlement to choice and control. This also demonstrates that even though this philosophy is embedded into policy, practice is clearly lacking progression. Although policy espouses principles that may be simple to express, they are often highly complex to translate into practice and can cause translation loss and mischaracterisation.

Mansell and Beadle-Brown (2004), and others (e.g. Towell and Sanderson, 2004), state that systematic evidence is scant, beyond case studies showing improved outcomes following implementation of person-centred approaches. However, Emerson and Stancliffe (2004) argue that the literature on positive behaviour support (Lucyshyn et al., 2002) and active support (Jones et al., 2001), as well as that on the development of individualised services for people with autism, provides sufficient evidence to show that individual planning and action result in positive benefits to people with learning difficulties. They believe that this evidence is generalisable to person-centred planning. Robertson et al.'s (2005) major study has confirmed this. They write:

> The results of the formal evaluation indicated that PCP is both efficacious and effective in improving the life experiences of people with learning disabilities. PCP also reflects the core values of empowerment and personalisation that underlie contemporary approaches to health and social care in England.

3.17 Ethical and Value-led Training

In recent years, social care practice has seen a rise in value and ethical-led training; as a result, awareness of this, and of recognising our own values and the values of those that practitioners are supporting, is becoming increasingly important. Ethics training potentially helps practitioners better understand themselves, helps them to express their decision making processes more clearly and helps individuals to hold themselves to moral account. I believe that by valuing and recognising the role of values in decision making we can help create a more autonomous and empowering decision making process for all decision makers, service users and practitioners, managers and leaders alike. Ethics training also assists practitioners in gaining the capacity for moral reflection and doesn't just stress the importance of having ethical awareness; through education and experience practitioners gain the ability to continually analyse and critique their practice and to take this with them into the future, which they describe as a "habit of constructive analysis".

It is suggested that the theory-practice gap is still problematic (Seedhouse, 2009) in training ethics and it requires more innovative approaches. We have seen a rise in computer-based e-learning programmes, yet this still appears to be a developing field of research, and I would argue that face to face training is warranted more than computer-based programmes in order to contextualise the matter and allow more understanding of the topic to be guaranteed.

3.18 PBS as a Treatment Model

A fundamental characteristic of PBS is its emphasis on interventions that involve manipulations of antecedent conditions, including substantial lifestyle adjustments intended to achieve multiple outcomes. In PBS training this characteristic remains highly generic by focusing on a broad range of environmental changes, as opposed to ABA, which relies on a technical rationale for why such changes might be expected. This is one of the counter-

arguments from the ABA field: that PBS lacks rigor in research and empirical data. ABA specialists consider antecedent conditions to require a considerable amount of expertise to manage such complex situations and therefore they suggest there is a need for reliable data to make such serious and life changing decisions.

The ABA specialists cite that PBS leaders are providing an intervention model that appears to be non-technical in nature. ABA argues that PBS is marketing its model to service providers who typically lack formal training in ABA and thus the model avoids presenting complex procedures. ABA, on the other hand, has a multitier approach to intervention in which formally trained and certified professionals are, in principle, available to provide guidance, assistance and monitoring to those who lack such expertise. The counter argument to this, however, is that the industry is seeing a decline in these professionals and commissioners of services lack the economic facilities to fund such specialisms, which renders PBS a more attractive offer and solution.

Another PBS characteristic is its emphasis on behavioural support and adjusting the environments to provide accommodations for people with disabilities. The purpose of this is to increase the range of opportunities and activities for the person and it requires less clinical expertise from a behaviour specialist. Again, this is an attractive offer to commissioners from a funding viewpoint. The disadvantage of this can result in misunderstanding of the behaviour function and thus the behavioural support and adjustment is inconsistent with the function. From an ABA perspective, this necessitates hypothesising and analysing before implementing. Baumeister (2004) challenged this by arguing that PBS is re-conceptualising clinical services and risk minimising the need for expertise in ABA. He considered this to encourage the de-professionalisation of learning disability services.

Given the wide range of disciplines in PBS, some would argue that practitioners should be trained in a range of aspects to ensure both the efficacy and fidelity of treatment, including systems analysis, ecological psychology, environmental psychology etc., as well as the values embedded in various social movements such as normalisation, inclusion, person-centred planning etc. (Carr et al., 2002; Horner, 2000). It is also worth highlighting here that while PBS has elements of ABA, the practitioners should also be well versed in these behaviour science methods that currently have no policy stipulation.

The differences in how PBS and ABA approach practitioner training are clearly significant. The risk inherent in the PBS approach is that services may not adequately incorporate the findings of decades of research in behaviour analysis because its practitioners lack the necessary training in ABA. This risk is exacerbated by the failure of many proponents of PBS to acknowledge the foundation of PBS in ABA and vice versa; PBS supporters state that PBS offers a more practical solution to today's community and the community itself is a research field and is promoting evidence-based empirical data.

3.19 Enhancing Quality of Life

Autism and behaviours of concern independently contribute to lower quality of life scores for individuals (Beadle-Brown, Murphy and DiTerlizzi, 2008). The construct of quality of life (QOL) has a complex composition based on whether a person has autism or not and it is worthy of defining; however, despite 40 years of research in this area it still lacks an agreed definition. For the purpose of this research, Cummins' (1997) Comprehensive Quality of Life Scale (ComQol-A5) has been adopted, which is still relevant today. Cummins provided a definition of QOL in an attempt to operationalise this into practice:

> Quality of life is both objective and subjective, each axis being the aggregate of seven domains: material well-being, health, productivity, intimacy, safety, community, and emotional well-being. Objective domains comprise culturally-relevant measures of objective well-being. Subjective domains comprise domain satisfaction weighted by their importance to the individual.

With regard to PBS, QOL is its primary goal in that it aims to support the person in achieving a comprehensive and durable lifestyle change. The reduction of behaviours of concern, although important, is considered a secondary goal. Although these goals are primarily for the person, the quality of life goal is also applicable to their support staff. This is the first practice model to include the wellbeing of support staff and it considers the causal links between staff wellbeing and the person with behaviours of concern.

Quality of life is depicted as the core 'dependent variable' and sometimes referred to as 'subjective well-being'. The use of person-centred planning is therefore critical to understanding the quality of life goals for each person. PBS encapsulates this core variable within person-centred planning into three themes: happiness, helpfulness and hopefulness. To measure quality of life, PBS relies on its behavioural roots to insist upon careful measurement and evaluation to determine the fidelity and effectiveness of an intervention (Dunlap et al., 2008). Impediments to quality of life in PBS terms are considered to include behaviours of concern, skills deficits and dysfunctional systems (Carr, 2007).

Proactive behaviour support strategies are used to enhance quality of life and these include: adapting the environment, teaching programmatic skills to increase independence, developing focused support strategies to reduce escalation in behaviour and implementing short term behaviour change interventions. These proactive strategies have a long-term focus and aim to prevent the problem from occurring in supportive environments. Evidence-based practice has proven through a PBS framework that when a person's needs are met (rather than problem behaviours managed) quality of life will improve and this will assist to reduce or eliminate behaviours of concern; nonetheless, leadership and management is required to promote this (LaVigna and Willis, 2012).

3.20 Critical Evaluation of Leadership and Management Theory and the Integration of PBS into Practice

There has been some fundamental mistakes concerning leadership and management within the literature and it is worth exploring these further in order to understand the deep components of the phenomenon. Applying these to leadership and management theory will help to illuminate the key factors so that a practice framework can truly respond to the community of practice, reliably offering solutions and stopping these systemic failures from occurring again.

A key role of frontline managers in autism services is to ensure good quality support to people with autism by recognising and interpreting practice, regulation and inspection and the necessary competencies required to undertake the role. Practice leadership (PL) is a new concept in learning disability services; it is growing in influence in positive behaviour support and is closely associated with the work of the late Professor Jim Mansell. Commenting in his seminal research on community placements for complex needs people moving out of long stay hospitals (Mansell, 1994), he said: "Perhaps the most difficult part of the interventions was redefining the role of the house managers and area managers as primarily concerned with 'practice leadership' rather than administration".

Considering Mansell's statement, good managers and leaders should have full command of their role, however, research that demonstrates this has been fragmented. Adair's (1973) research into action-centred leadership can offer some insight here. This theory considers how it divides leadership into "task, team and individual". Each of these elements plays an important role in the leadership picture. The literature has shown a disconnection between leaders, managers and practitioners; therefore the vision at a macro systems level is seriously affected. Managers and staff start to work against each other and sub-cultures are created that are inconsistent with the vision. This was most noticeable in Winterbourne View. Exo level decision making became distorted and eventually inappropriate decisions were made. A lack of leadership and management therefore caused the slippery slope to abusive practice and the meso level practice norms were re-shaped and reactive-led.

Where action-centred leadership is most effective is when there is a balance between all three leadership divisions. Winterbourne shows us a complete imbalance, with staff overpowering leaders and managers, teams being reformed and tasks being re-shaped according to staffs' attitudes and culture. This balance created abusive results, built power over approaches and reduced quality standards.

In Mansell's later work, 'Challenging Behaviour: A Unified Approach' (2007) and the Mansell Report: 'Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs' (2007), there is an acknowledgement of the lack of practice leadership due to no strategic focus on building the capacity of skilled leaders in the community of practice. As a result, Mansell reported that commissioning processes had been affected and there were increased hospital admissions due to services not being sufficiently skilled to support people who challenge.

Training in leadership and management has been slow in social care and although most managers now require a Diploma in Health and Social Care (QCF Level 5), this falls short of application in practice. Adair believed that leadership skills are trainable and transferrable, which of course they are; yet this can also have a negative causal affect in the community at a chrono systems level when socio-historical careers require improving and this takes time to positively influence and requires more than training.

Transferrable skills can make positive and lasting changes, but equally so can socio-historical experience, such as working within more institutionalised settings, thus transferring this practice into another service area. Training and transferring skills still requires core leaders being visible in services and knowing what 'good' looks like in practice. Without this, the whole ecology system is at risk.

Research was conducted by Beadle-Brown et al. (2014) where a questionnaire measured practice leadership in order to examine its effects upon the implementation of active support. This research defined practice leadership as:

> The development and maintenance of good staff support for service users through managers: spending time observing staff work and providing feedback and modelling good practice; providing staff with regular one-to-one supervision; and team meetings focussed upon improving service user engagement and staff-service user relationships.

This line of research was further explored by Deveau and McGill (2014) and, like Beadle-Brown et al., the PL measure demonstrated that staff have better work experience of challenging behaviour and better implementation of positive behaviour active support. This research provided positive findings due to the environment being well understood by the participants and aspects of performance agreed by staff so that they had ownership of the project. The workforce interpretation is therefore consistent with the organisation's vision. This is central to the Action Centred Leadership Theory.

Frontline managers in autism services are often called upon to exercise both management and leadership skills. In reality, however, managers are monitored and incentivised almost entirely based on their management role, the organising and monitoring implementation of routine policies and procedures. It is common in the service to find managers who rarely come out of, or are expected to come out of, their offices and get involved 'on the floor'. This therefore provides little opportunity for direct leadership and management.

In this situation we can consider a number of theoretical perspectives. The literature has informed us that the competency of the workforce has not caught up with the demands of the role, therefore work is redistributed to less experienced staff where increased burnout is created. This also causes quality concerns and eventual abusive practice being exposed within the community. This reinforces societal attitudes that all social care is poor.

Conversely, we have to consider the motivation for managers to get involved 'on the floor'. Herzberg's Motivational Theory (1959) offers some insight in this regard. The hygiene

factors for the manager should offer the foundation for motivation, however, when damaged or undermined, the manager has no platform. We have seen a lack of PBS policy, supervision of good practice and fragmented relationships with supervisors, resulting in diminished working conditions. Increased administrative duties, taking managers directly away from the 'floor' therefore reduces motivators such as recognition, personal growth, advancement etc. Succession planning in the social care industry has been directly affected by this and we are now experiencing a national crisis in recruitment. The lack of economic investment in staff salaries has led to a huge shift, with many practitioners leaving the industry, which has depleted the experience pool, tacit knowledge translation and transference of practice even further.

In his study, 'Six Core Strategies to Reduce the Use of Seclusion and Restraint Planning Tool', Huckshorn (2005) identified leadership as the primary core strategy, which he considered critical to any organisational change strategy implementing PBS. He recommended that a behaviour reduction goal must be clearly enshrined and explicit in the organisational policies and mission statement, whilst producing a clear plan that targets this objective. This plan should be signed and activated by senior management who are then accountable for their actions. Huckshorn suggested that the more explicit the commitment, the more powerful the message is.

'The psychological contract' is an increasingly relevant aspect of workplace relationships and wider human behaviour and it can be synthesised with Huckshorn's research. Argyris and Schein illuminated this theory in the 1960s, focusing on organisational and behavioural theory. The previous theories considered visions, policies and motivators, however, Huckshorn (through policy dissemination) was also indirectly considering the psychological contract. Huckshorn was in effect proposing developing the relationship between the employer and the employees through mutual expectations, explicit mission statements and clear plans and objectives. Like action-centred leadership and achieving the 'right balance', the psychological contract in Huckshorn's research is seen from the standpoint of the feelings of employees, although a full appreciation requires it to be understood from both sides.

In a report by the Department of Human Services in Australia, 'Positive Behaviour Support Framework' (2011), there was continued evidence of the use of leadership theory using Adair's action-centred leadership. This included core functions of leadership, which were considered vital for the success of PBS across its services:

- Monitoring best practice and developing emergent new iterative standards through a standardised referral system, assessment, implementation and PBS review process;
- Developing and measuring against individuals' key performance indicators in relation to positive behaviour support planning and in the reduction of restrictive practices across the organisation;
- Developing and evaluating effective data collection systems to inform practice and demonstrate accountability in relation to positive behaviour support and the use of restrictive practices;

- Developing and demonstrating consistency between education/training and practice and incorporating evidence-based research;
- Developing and clarifying ongoing leadership, clinical governance and strategic planning in relation to positive behaviour support, the reduction of restrictive practices across services and ensuring this is explicit in policy.

In their statutory guidance, 'Positive and Proactive Care: reducing the need for restrictive interventions' (2014), the UK Government outlined the statutory responsibilities placed upon commissioners and executive directors. This included:

- A board level lead member must be identified for increasing the use of recovery-based strategies and PBS approaches with the explicit aim of reducing restrictive interventions;
- Executive level to lead on the strategy who is competently qualified;
- Boards to be accountable for restrictive intervention reduction programmes and to review both policy and practice annually. This also includes the development of action plans and audits of PBS plans;
- Executive boards must approve restrictive intervention reduction to be taught to their staff;
- Governance structures and transparent policies to show goodness of fit with the organisation and be accessible to all stakeholders;
- Annual reporting to commissioners who will monitor and act in the event of concerns.

Research has shown that organisations that do not promote good teamwork or open communication between the service and leadership team increase the risk of developing 'toxic environments'. A toxic environment tends to lack vision and leadership, does not support learning and development, lacks good systems for communicating and monitoring practice and tends to be introspective rather than positive and solution focused (Colton, 2004; Huckshorn 2005; Nunno et al., 2011). As a result of these toxic environments, organisations increase their risk of misusing restrictive practices and, as we have seen over the past three decades, this leads to the abuse of vulnerable people (Paterson et al., 2011).

Toxic environments do not occur overnight and they often develop over the long-term. To understand this concept, Dunham and Pierce's (1989) Leadership Process Model can be considered. The casual effects of toxic environments can be considered in the relationships between the four key factors of Dunham and Pierce's model. These are:

1. The Leader: This is the person who takes charge and directs the group's performance. However, in the case of a toxic environment the leader is not present, often lacking in vision and direction themselves due to no clear organisational policy or a lack of leadership capabilities.

2. Followers: These are the people who follow the leader's directions on tasks and projects. In the case of the toxic environment, followers create their own rules, norms

and beliefs, which ultimately create a change and decline in practice standards, as seen in Winterbourne View.

3. The Context: This is the situation in which the work is performed. The physical environment lacks maintenance and becomes sterile and uninviting, resources are reduced or staff become unmotivated to ask, and events in the wider organisation become restricted.

4. Outcomes: These are the results of the process. Outcomes could be reaching a particular goal, e.g. improving people's quality of life and restraint reduction. This can also include things like improved trust and respect between the leader and followers, or higher team morale. However, conversely, in a toxic environment the literature demonstrates high levels of restraint, staff turnover and conflict between leaders, managers and staff.

Most importantly, what a toxic environment highlights is the lack of leadership as a dynamic and ongoing process.

Research and current thinking has enabled leaders in service provision to use this evidence-based literature to inform their leadership structures and processes. In comparison to this, in the Faculty of Medical Leadership and Management publication that reviewed the NHS Leadership Development Programme 'Leadership and Leadership Development in Health Care – The evidence base' (2015), Professor Michael West said:

> One observation to come out of this work is that much of what is written about leadership and (the millions of pounds spent) on leadership development in the NHS is based on fads and fashions rather than hard evidence… The evidence is clear though: leadership at every level – from frontline leadership in wards, primary care and community mental health teams to board leadership in trusts to national leadership in overseeing bodies – is influential in determining organisational performance.

In their joint policy guidance, 'Positive and Proactive Workforce: a guide to workforce development for commissioners and employers seeking to minimise the use of restrictive practices in social care and health', Skills for Care and Skills for Health (2014) addressed organisational leadership values and cultures by identifying the work of the Institute for Public Care (2012): 'Leading the Way: the distinctive contribution of the not-for-profit sector in social care'. The institute advocated that evidence-based research must be applied within the leadership model of an organisation that is developing a PBS model. A number of key factors were highlighted within the guidance:

- To promote a culture of person-centred approaches and ensure that the service user is at the centre of everything;
- To operate a culture of openness, respect and transparency in all areas of practice;

- Organisational leadership and the leadership team to be fully committed to identifying reasons for behaviour and promote minimising the use of restrictive practices through person-centred working;
- Management teams to have systems that are fit for the purpose of restrictive practice and be aware and in touch with the reality of practice;
- Leaders to promote a learning culture from practice, sharing and celebrating good practice and also promoting a proactive response to bad practice.

It is widely recognised in the literature on PBS and leadership that PBS lead practitioners act as change agents by leading, guiding and supporting staff to effectively implement PBS. Their role is one of knowledge translation and transference and it is considered a complex and multi-dimensional concept that needs further and deeper discussion.

'Knowledge translation' is a new term in the social care field and it was defined by the Canadian Institutes of Health Research (2005) as:

> the exchange, synthesis and ethically-sound application of knowledge – within a complex system of interactions among researchers and users – to accelerate the capture of the benefits of research through improved health, more effective services and products, and a strengthened health care system.

This definition was also applied to social care by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) in the US in 2005: "the multidimensional, active process of ensuring that new knowledge gained through the course of research ultimately improves the lives of people with disabilities, and furthers their participation in society".

PBS practitioners promote an interactive and iterative process, underpinned by effective exchanges between them and the support teams. Working together to bring theory and practice closer creates new knowledge and leads to the creation of bespoke behaviour plans. This approach also has its weaknesses, however, and it can be influenced by social norms, attitudes and cultures, which highlights the complexities and multi-dimensional factors. As a result, PBS practitioners need to be multi-skilled in their practice. Currently, there is no nationally accredited qualification for PBS practitioners, unlike applied behaviour analysis, therefore the community has some way to go before this can be remedied.

Knowledge translation from a PBS practitioner viewpoint may consist of a number of factors, for example:

- Knowledge dissemination of the PBS principles;
- Communicating policy message;
- Knowledge management and utilisation;
- Two-way exchange between practitioners and those who apply knowledge;
- Synthesis of results and service user context;
- Development of consensus guidelines in a PBS plan.

This sophisticated approach is embedded in the actual contexts in which the knowledge applications will eventually occur, thereby bridging the leadership and practice gap and being much more impact-orientated.

Organisational structures can affect the dynamics of knowledge translation and transference and this can result in a shortfall in outcomes for a PBS practitioner. This is largely due to the practitioner working in a team and not having any direct line management of the service manager. Without the drive of a clear PBS policy, managers may feel threatened by the insistence upon making changes to the environments and the synthesis of theory and context may be avoided due to lack of understanding or fear of change. This is possibly more noticeable at the micro and meso systems level and can affect practice standards, transparency of communicating the PBS message and workforce cohesiveness. Therefore, knowledge translation and transference can be seriously undermined.

In an attempt to improve knowledge translation, the Government of Victoria in Australia provided leadership guidance in 'Positive Practice Framework: a guide for behaviour support practitioners' (2011) in which they highlight the Collective Leadership Model. This model for individuals with an autism spectrum disorder has since been adopted by the Department of Human Services, Melbourne, and reflects an attempt to be more interactive with knowledge translation:

- Creating a participatory process by defining roles and responsibilities and providing staff with clear expectations;
- Collaborative decision making so that all levels are fully involved and empowered;
- Planning and systems promote a culture of feedback and learning;
- Transparent distribution of resources;
- Facilitates consultation and involvement.

In 1994, Mansell was forward thinking in his vision of management and leadership theory in positive behaviour support, and research over the past 10 to 15 years (as a result of serious case reviews) confirms the value of understanding, which had been seriously underestimated.

3.21 Governance – A Systems Theory Perspective

Before I discuss governance in terms of PBS, a theoretical perspective will be addressed. Governance, like ethics, seeks to understand the way we construct collective decision making, whereas governance theory is about the practice of decision making. The difficulty that the literature brings is that governance is vaguely described and its application is not specified. This thesis does not intend to fully investigate governance theory however, but instead to provide a brief overview from a systems theory perspective.

In social and political research, governance is discussed in a variety of ways (Jordan et al., 2005) and the theoretical diversity is therefore too great. This may be more of a discourse problem with language than a problem with the theory, however. The major advantage of

governance theory is that it provides a framework in order to cover a broad array of institutional arrangements and mechanisms by which the coordination, regulation and control of ecological systems and subsystems can be conceptualised. The argument here is that governance has potential as long as it's not conceptualised as a holistic macro structure, referring to the functional logic of the whole organisation. Governance structures need to link macro and micro systems, and to specify concrete procedures to ensure they steer in the right direction or information will get lost in translation.

Governance theory can be considered a modern variant of system theory – a structural, institutional approach on the various forms of social coordination and their combination. From such a perspective, societies generate social and political order not only through central decision making and top-down control, but also by local interaction and horizontal coordination.

From a macro viewpoint, this could be dissolved into a multiplicity of conflicting groups and/or individuals, which could lead to power struggles within society and government. Applying ecological systems theory here demonstrates the dynamic character of interdependencies and interactions between social actors and the complexity of relations between the components of the system. The various layers this creates within the system and the emergent relations between the levels therefore needs to be considered. The challenge for leaders is to integrate these various layers into a single picture. Governing agents (leaders) who provide incentives and motives at the micro level are an important component in the explanation of steering regulation processes at the macro level.

The complexity deepens as these agents are embedded into political, economic and cultural rule systems that distribute resources and rights. Equally, this extends to the exo system and it may affect the wellbeing of people within the organisation, and this is further complicated as it is hidden due to staff having no tangible interaction with these rules. Offering explanatory flowcharts and diagrams in which the relative casual flows and major relationships between major components and their embeddedness into procedures are explained can go some way to clarifying the situation.

3.21.1 PBS governance

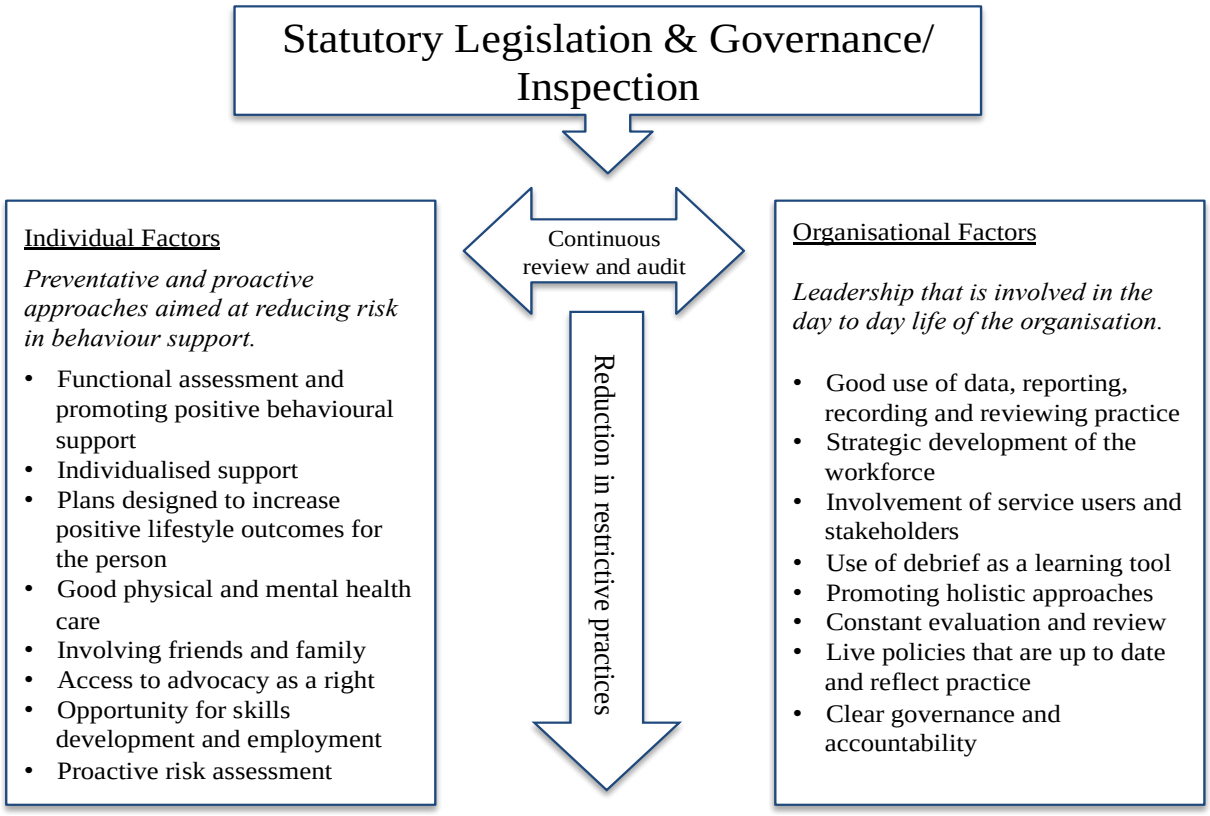
As described earlier, the leaders of organisations supporting people with behaviours of concern can only monitor and govern practice if they are actively involved in the day-to-day issues and are capable of doing so. The literature has demonstrated all too often the quality of life outcomes when leaders do not develop 'fit for purpose' quality assurance systems. There also seems to be gaps in the literature with respect to governance in PBS and we are yet to see adequate evidence-based research in this area.

A PBS governance system in organisations must ensure they are accountable for continuously improving the quality of their services through high standards of policy and practice. This includes embedding the vision of restrictive reduction into its corporate functions, explicitly showing the strategic direction to stakeholders and the workforce, managing proactive risk,

improving practice performance and ensuring compliance with statutory requirements and practice standards set by the organisation.

To identify the components of PBS at both an individual and organisational level, Figure 3 addresses this against the statutory and governance framework for restrictive practice reduction.

Figure 3: Framework for Reducing Restrictive Practices and Promoting Positive Behaviour Support (Paley, 2012), BILD



The practice of governance should be modelled by leaders and managers to promote an understanding that the PBS Framework is a 'whole system' that entails shared responsibility, from the most senior to the most junior staff member. Research has informed practice that shared responsibility and accountability for quality, continuous improvement, minimising risks and fostering environments that are positive and thriving, all promote behaviour reduction.

The Department of Health's (2014) 'Positive and Proactive Care: reducing the need for restrictive interventions' was revised as a result of the Winterbourne View (2011) documentary. The aim of this publication is to provide rigorous guidance on the use of effective governance within a PBS practice model. Effective governance frameworks are only successful when founded on transparency and accountability, even more so when supporting people who may require a restrictive intervention. Governance arrangements for UK service providers require organisations to:

- Inform commissioners and relatives of the name, contact details and qualifications of the lead PBS practitioner;
- Demonstrate and evidence board reviews of restrictive reduction;
- Report on progress to the board and commissioners on restrictive reduction;
- Organisations must demonstrate a quality review of PBS plans, which must also be included in the internal quality assurance system.

3.22 Training a Capable Workforce in PBS

PBS training is fundamental in promoting and supporting systems change for people with behaviours of concern and it has been shown to be effective in minimising more serious risky behaviours (Totiska et al., 2010). There has been little research into PBS training due to greater focus on physical intervention training and even less research conducted on how PBS has contributed to improving quality of life. As evidence-based literature is rare, the Department of Health advised that further research to shed light on this phenomenon was required due to the current struggles for people with behaviours of concern, however, little has progressed.

The Mansell report (2007) recommended the introduction of a training framework for health and social care professionals and support staff. Mansell advised that supporting complex needs required more specialised competency-based training so that people who present with behaviours of concern are enabled to remain in their own homes and communities. A focus on training staff in how to develop and sustain capable and functionally appropriate environments is key to the success of service placements. However, the report did not venture to describe the vast array of training required.

More recently, the World Health Organisation (WHO) reported in 'Autism Spectrum Disorders and other Developmental Disorders' (2013) that:

> People with ASD and their families are in need for increased access to evidence-based psychosocial interventions that have shown to be effective in improving behavioural outcomes and functional adaptive skills such as training and support. At the organisational level, involvement of policy makers and training institutions such as universities, governments and professional associations has proven to be the key element for sustained training initiatives. At a workforce level, the development of training materials and programmes for a variety of care providers is being reviewed as essential to strengthening human resource capacities in countries. Training needs to be evidence-based in content and offer a competency-based approach.

When staff lack knowledge about the causes of a person's behaviour of concern, this often goes hand in hand with a lack of confidence in dealing with challenging situations. As a result, staff are much more likely to be negatively affected when supporting people who challenge and therefore this affects their relationship with the person who is challenging. Training thus requires a preventative and reactive approach. Educating staff to help them

understand the reasons for behaviour will reduce negative thinking. This will also lead to better relationships and ultimately a reduction in behaviour.

Training requires the development of knowledge and skills through evidence-based, experiential application, which is much more powerful than classroom teaching and successful in developing and reinforcing workforce competency. Contextualised PBS training requires 'in vivo' problem solving within real life contexts. Training that involves providing staff with a generic list of intervention techniques can no longer be considered adequate, but rather it should embed behavioural science within person-centred contexts to effect systems change. Optimum learning is therefore achieved when staff are able to apply theory to clinical practice, thus bridging the 'translation gap'.

A large proportion of PBS training needs to focus on the functions of behaviour and the contributing factors within the environmental context. The casual explanations of a person's behaviour may change as the staff consider additional factors that are placed within a functional and holistic PBS framework. Training staff to a high degree of skill will not, on its own, lead to high quality support. The organisation needs to have the structures and culture in place to support the application of those skills (Institute for Public Care, 2012). PBS training, as with the PBS Practice Framework, therefore requires a multi-dimensional approach to address cultures, values and attitudes in order to avoid toxic environments forming.

Skills for Care and Skills for Health published guidance 'A Positive and Proactive Workforce' (2014) in conjunction with the Department of Health 'Positive and Proactive Care' (2014) to address training. Both publications addressed the need for explicit learning outcomes relating to:

- The lived world experiences of people using services as 'experts by experience';
- Building therapeutic relationships as a core skill;
- Principles of PBS;
- Functions of behaviour;
- Staff experiences, thoughts and feelings, or experiencing behaviours of concern;
- Alternatives to restrictive practice using proactive strategies;
- Legal and ethical issues;
- De-escalation techniques;
- How to reduce the risks of restrictive practices and also identify when practices are becoming more aversive;
- The use of breakaway techniques and physical interventions;
- Post incident de-briefing and support to both the person who challenges and their support staff;
- Mental Capacity Act training;
- Human Rights-based approach.

This training content is specific to settings where people may require the use of restrictive interventions and it is unlikely that a single training programme would be a harmonious fit in

all health and social care settings. NIHCE (2015) offered guidance on the core components of training:

- Person-centred daily activities (person-centred planning);
- How to adapt a person's environment and routine;
- Developing alternative strategies to behaviour (e.g. communication skills, emotional regulation and social interaction);
- Stakeholder participation and consultation;
- Early preventative strategies and de-escalation techniques;
- Reactive strategies when there is no alternative.

In 2013, NIHCE also published 'Autism: the management and support of children and young people on the autism spectrum'. Although this guidance was primarily for children and young people, the principles could be applied to the adult sector. NIHCE promoted the following training and skill acquisition for staff:

- The nature and course of autism;
- Communication and sensory processing skills;
- The nature and course of behaviour that challenges in people with autism;
- Recognition of common coexisting conditions (e.g. mental health, anxiety, depression, physical health problems, epilepsy, sleep problems, ADHD);
- Transition (e.g. day to day movement, generalising skills in different settings etc.);
- The impact autism has on the person and their families and support staff;
- The social, physical and sensory environment and the impact this can have on the person living with autism;
- How to assess risk (e.g. behaviour, family/service breakdown, exploitation or abuse);
- How to develop and design effective autism specific environments and support plans.

All national and international guidance promotes a similar range of training content, but they stand unified on the promotion of continuous learning opportunities, with regular clinical and supportive supervision. Building this into the PBS Practice Framework will provide the ingredients for capacity building that will lead to sustained changes in clinical autism practice.

3.23 Conclusions

The literature review highlighted the complexities of autism spectrum condition and identified the epidemiology of autism in the UK. It noted the consequences of the condition from a cost point of view, as well as the practice implications of restrictive physical intervention. The literature discussed the recent serious case reviews and subsequent changes in both national and international policy. The research questions and research framework were synthesised, using Bronfenbrenner's Ecology Systems Theory with the literature in parts to move beyond an understanding of the phenomena to a deeper exploration of the situation.

Government policies and research within the field were used to illuminate the national and international perspective on PBS, which was then triangulated into practice themes that would assist in the creation of the PBS holistic framework. The chapter then explored the concept of 'lost in translation' and particularly focused on the policy and practice gap.

The final section of this chapter was dedicated to PBS and a critical review of the literature on PBS as a model, intervention and how this is integrated into policy and practice from a governance and training perspective. A focus on the philosophy of ethics and values within a person-centred approach illuminated what could be adopted within a 'toolbox' or holistic practice framework to aid ethical decision making. Finally, a deeper exploration of the literature concentrated on leadership and management and the theoretical perspectives, which helped to illuminate the complexities, and moving beyond a simple understanding was considered.

CHAPTER 4: METHODOLOGY

4.1 Introduction

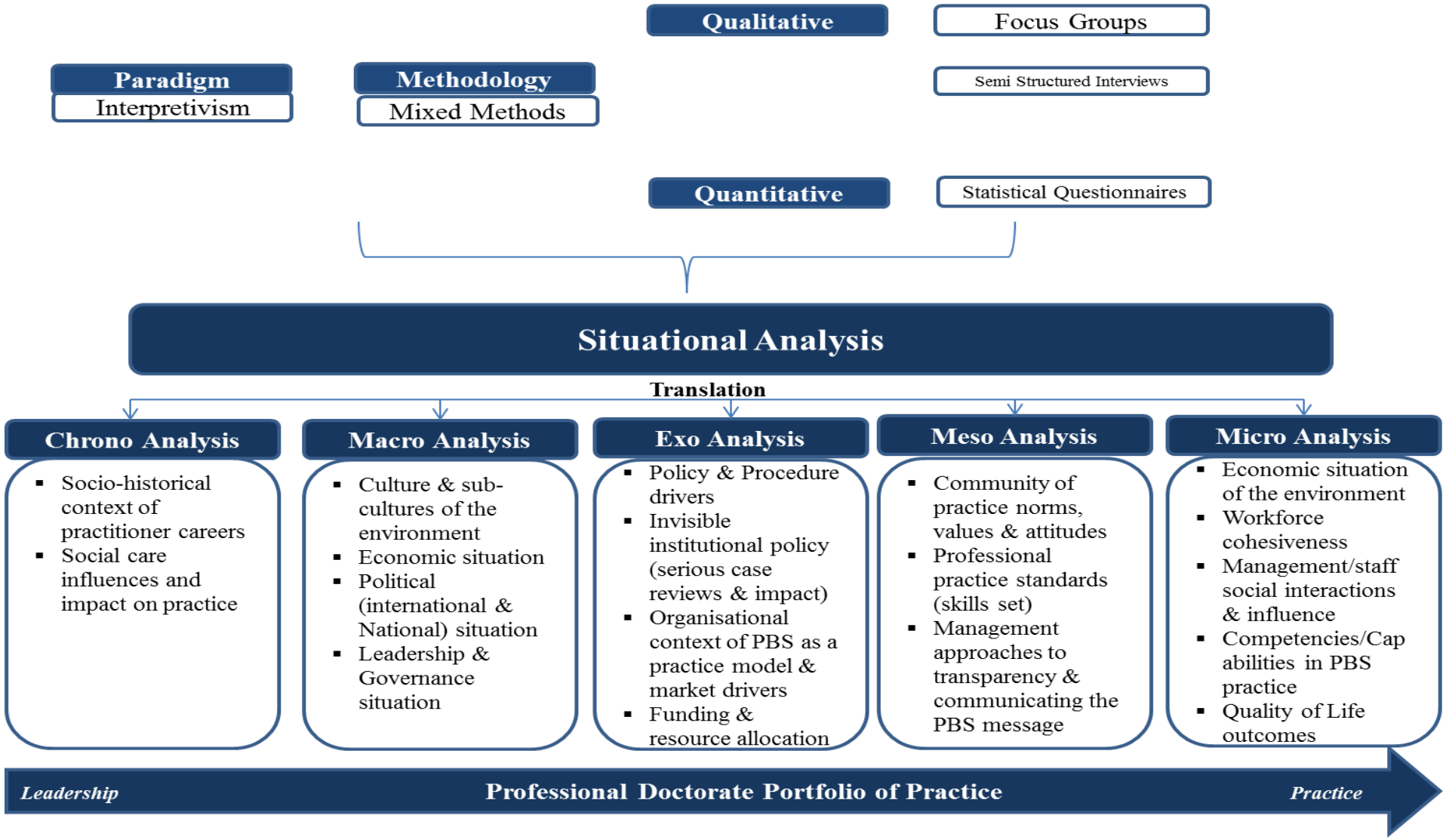
This chapter provides an overview of the research design adopted in this study using situational analysis as the single methodological approach. The professional doctorate study structure (Figure 4) of the research framework is presented, broken down and synthesised with Bronfenbrenner's Ecology Systems Theory, to provide a holistic summary of the research structure. A clear justification of the epistemological and ontological position of this research is discussed, along with the positionality of the researcher. Research ethics are presented, describing the importance of being 'morally active' throughout the study.

An epistemological background of situational analysis is discussed at length in this chapter, addressing the differing theories throughout the evolution of this methodological approach. This discussion transports the theoretical perspectives and brings them up to date, focusing on Clarke's (2005) theory of pushing grounded theory around the postmodern turn. Situational, social world/arenas and positional mapping are illuminated and their use explained in the course of this study. Discourse analysis and reflexivity are presented as essential approaches that complement the adoption of situational analysis as a methodology.

Mixed methods was considered the appropriate approach in this work as this provided methodological triangulation of the research findings; therefore the chapter describes the qualitative and quantitative methods used. The data collection methods adopted focus on semi-structured interviews, focus groups and questionnaires. The selection of participants and data analysis completes this discussion.

As this chapter comes to a close, attention is placed on the role of the researcher, the research procedure itself and how situational analysis supported the direction of the study. Finally, I conclude this chapter by discussing authenticity and trustworthiness.

Figure 4: The Professional Doctorate Research Framework for a Holistic PBS Practice Framework for Autism Practitioners



4.2 Philosophical Foundation

The foundations of good research rely on giving detailed attention to certain philosophical factors. If these factors are overlooked, the research will be open to criticism and the quality of the findings will be challenged. Denscombe (2010) offers clarification on the philosophical assumptions that constitute the foundations for research in the way that:

- They underpin the perspective that is adopted on the research topic;
- They shape the nature of the investigation, its methods and the questions that are asked;
- They specify what type of things qualify as worthwhile evidence;
- They point to the kind of conclusions that can, and cannot, be drawn on the basis of the investigation.

This clarification by Denscombe demonstrates that the philosophical foundation is central to the research process itself and it needs to be explicit from the outset. The following discussion outlines the foundation that underpins my research questions.

4.2.1 Interpretivist paradigm

Interpretivism was developed as a response to the objectivism and excessive rationalisation of the positivist approach (Willis, 2007). Accordingly, "interpretive researchers assume that access to reality (given or socially constructed) is only through social constructions such as language, consciousness, shared meanings, and instruments". Development of interpretivist philosophy is based on the critique of positivism in social sciences.

Interpretivism is associated with the philosophical position of idealism and is used to group together diverse approaches, including social constructivism, phenomenology and hermeneutics, approaches that reject the objectivist view that meaning resides within the world independently of consciousness. According to the interpretivist approach, it is important for the researcher as a social actor to appreciate differences between people. Moreover, interpretivist studies usually focus on meaning and may employ multiple methods in order to reflect different aspects of the issue.

In order to understand the rationale in opting for the interpretivist paradigm, this research analysed the opposing assumption against the aims of the research stated in Chapter 2:

Table 6: Comparison and Rationale of the Research Assumptions

	Positivist	Interpretivist	Rationale for Research
Ontological Assumption: ▪ Nature of reality	▪ Objective and tangible of the real world ▪ Single external reality	▪ Socially constructed ▪ No single external, but rather multiple.	Multiple realities within the ecology systems and research framework. Interpretivist paradigm allows for depth of study.
Epistemological Assumption: ▪ Grounds of knowledge/ relationship between reality and research	▪ Possible to obtain hard, secure objective knowledge ▪ Research focus on generalisation and abstraction ▪ Thought governed by hypotheses and stated theories	▪ Understood through 'perceived' knowledge ▪ Research focuses on the specific and concrete ▪ Seeking to understand specific context	Understanding perception and context offers insight into what has been lost in translation, how social influences impact the community etc.
Methodology and Researcher Positionality	▪ Concentrates on description and explanation ▪ Detached, external observer ▪ Clear distinction between reason and feeling ▪ Strive to use rational, consistent, verbal, logical approach ▪ Seek to maintain clear distinction between facts and value judgments ▪ Distinction between science and personal experience ▪ Formalised statistical and	▪ Concentrates on understanding and interpretation of phenomena ▪ Allow feeling and reason to govern actions ▪ Partially create what is studied, the meaning of phenomena ▪ Use of pre-understanding is important ▪ Accept influence from both science and personal experience ▪ Primarily non-quantitative	Allows for research positionality rather than being detached. Can explore interactions and interconnections of the various ecology systems theories and help to understand the different policy, competency and capability factors.

	mathematical methods predominant		
Methods	Quantitative Methods: ▪ Experiments ▪ Questionnaires, surveys ▪ Hypothesis testing	Qualitative Methods: ▪ Semi structured interviews ▪ Observations ▪ Focused groups	Allows for mixed methods to be adopted.

The main disadvantages associated with interpretivism relate to the subjective nature of this approach and the significant space for bias on behalf of the researcher. Primary data generated in interpretivist studies cannot be generalised since data is heavily impacted by personal viewpoint and values. Therefore, reliability and representativeness of data is undermined to a certain extent. However, the adoption of the interpretivist paradigm can be studied in a great level of depth to illuminate understanding.

4.2.2 Epistemological position

The epistemological stance on the interpretive approach in this research assumes that knowledge of reality is gained only through social constructions such as language, shared meanings, tools, documents, etc. This research has no predefined dependent and independent variables, but instead a focus on the complexity of human sense-making as the situation emerges (Kaplan and Maxwell, 1994).

This research focuses on understanding the social phenomena within the ecology systems of the research framework in the social contexts in which they are constructed and reproduced through their activities. The interpretative stance will allow this research to understand the context of the information systems within the chrono, exo, macro, meso and micro, and the processes whereby the information systems influence and are influenced by the context.

Using the interpretive perspective will enable this research to increase understanding of the critical, social and organisational issues related to the adoption of a PBS holistic practice framework.

4.2.3 Ontological position

Considering the choice of research methods and methodologies to gain knowledge largely depends on what extent we consider to be our relationship to reality. This involves considering the ontological position of this research. From a positivist

ontological perspective, all reality is meaningless, independent from human feeling, ideas and perceptions and scientific knowledge consists of facts. This is opposed to the interpretivist assumption that reality is meaningful and socially constructed by the individuals who participate in it (Willis, 2007). There is no one absolute thrust, but instead different truths and realities.

This research believes that reality is socially constructed by autism practitioners, leaders and managers who interact and make meaning of their world in an active way. This study therefore allows for the search of truth in peoples' lived experiences through interpretation.

4.2.4 Researcher positionality

The positivism assumption is not radically opposed in this study, nevertheless it is recognised that this research is strongly influenced by the epistemological and ontological stance of the researcher. It is recognised that the researcher believes that reality is socially constructed and that we can learn about it through the interplay between the subject and object of this study. This assumption allows me to become immersed in the natural setting and thus provide more opportunities for interaction with participants. I can therefore not be neutral.

Bias therefore remains a naturally occurring human characteristic; positionality in this research is used in the context of an inductive approach to social inquiry as an exploration of the researcher's reflection on her own placement within the many contexts, layers, power structures, identities, and subjectivities of the viewpoint (England, 1994). Positionality allows for a narrative placement for researcher objectivity and subjectivity whereby the researcher is situated within the many aspects of perspective and positionality (Lave and Wenger, 1991). This often serves to inform a research study rather than to invalidate it as biased or contaminated by personal perspectives and social or political viewpoints.

It is worth exploring the literature on 'embeddedness' here from the early work of Polanyi (1957), who considered the idea of embeddedness, or social embeddedness, to be represented by an organisation or individual's connection, relationship and/or position with the social network. McGinity and Salokangas (2014) described embedded researchers as "those who work inside host organisations as members of staff, while also maintaining an affiliation with an academic institution". The researcher's task is seen as collaborating with teams within the organisation to identify, design and conduct research studies and share findings that respond to the needs of the organisation and accord with the organisation's unique context and culture.

In later efforts, Provan et al. (2008) stated that the degree of embeddedness of an organisation refers to its structural position, and the greater its embeddedness or

'centrality' in an organisational arena, the greater the connectivity to information and resources. This can lead to greater trustworthiness and making decisions that are relevant and contextualised to the environment and the research. The advantage this also brings is the increased performance of both the organisation and the research as it matures and strengthens.

In the early work of Husserl, he outlined that what we understand as a phenomenon will depend upon how we examine the phenomenon and try to understand it. As the researcher, I am an embedded part of this process and my embedded stance will steer the research design and methods used to strive to make the implicit, explicit. The exception to this is that I occupy a managerial role in what is regarded as a practice-based setting, therefore my reflexivity will emanate from context rather than the positionality of stance. This position aims to reach a faithful expression of the phenomenon, to clarity and offer perspective, which are obtained from the phenomenon and from reflexivity.

A distinctive aspect of my contribution to practice is my embedded stance in terms of being part of the holistic experience of the people from whom I am collecting data. This can, however, create tension in terms of the management expectations over the research expectations within my day to day work and academic commitments. I am fully immersed in the setting and my positionality can have a number of advantages and disadvantages that need to be considered. These are outlined in Table 7 below:

Table 7: Advantages and Disadvantages of Researcher Positionality

Advantages of Research Positionality	Disadvantages of Researcher Positionality
▪ Embedded stance can help drive research forward within the community ▪ Access to participants at all levels – quality and quantity of participants is achievable ▪ Access to a full range of information ▪ Historical knowledge can help draw out pertinent points ▪ Research can be conducted in a more timely manner due to workplace and organisational objectives for PBS practice ▪ Access to decision makers strengthens embeddedness ▪ Capacity building for knowledge translation	▪ Competing forces and expectations between role of manager and clinical work ▪ Demands of management role takes priority and may lengthen clinical deadlines ▪ Participants may become suspicious over research interests and participant caution, over-highlighting controversy due to fear of recrimination ▪ Power imbalance between research and participant may cause confusion

Researcher positionality takes on an added degree of importance when research involves social interaction between a director and a participant from within the same community. For example, if we take semi-structured interviews, this method creates a distinct social dynamic, whereby differences between researcher and participant are brought into focus as a result of shared cultural knowledge. This is known as 'diversity in proximity', which effectively means that as an 'insider' the researcher is better able to recognise both the ties that bind the researcher and participant together and the social fissures that divide them.

My status can make me accepted within the group, but it can also affect the way in which others perceive me within this relatively close social arena in which we work. It can also illuminate fissures that may not be seen if one was not considered part of that community. Equally, we cannot assume that this also leads to greater proximity of participants in relation to their experiences, perceptions and feelings and in fact it may result in the complete opposite.

A further critical component is that of my own belief with regard to where I am positioned within my own community and the social dynamic that exists between the participants and me. I have long considered myself a 'practitioner' and this has provided me with an imagined sense of belonging. I can therefore be considered an 'insider', however, in this regard I did not anticipate the differences in opinion that led to me being considered an 'outsider'. This was largely due to the opposing ideologies and assumptions of the current context and also being considered more as a researcher than a director.

Identifying all of the above early afforded me time to reflect, examine and explain this within the findings. The advantage of this was that it illuminated these issues and brought both contexts closer together through the interface of semi-structured interviews and focus groups, as well as allowing for professional debate.

4.3 Research Ethics

The Economic and Social Research Council's (ESRC) six key principles of ethical social research (2015) were adopted:

1. Research should be designed, reviewed and undertaken to ensure integrity, quality and transparency.
2. Research staff and participants must normally be informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved.
3. The confidentiality of information supplied by research participants and the anonymity of respondents must be respected.
4. Research participants must take part voluntarily, free from any coercion.

5. Harm to research participants must be avoided in all instances.
6. The independence of research must be clear, and any conflicts of interest or partiality must be explicit.

Any research carries some risk, which varies according to the areas of research undertaken and the characteristics of participants, including researchers. Balancing risks against the likely benefits of high quality research is a major objective of good governance and should be practiced by conducting oneself to standards of behaviour that society accepts. Ethical clearance for this work was accepted by the University of Sunderland (Appendix B).

A key component of the work of a social care practitioner is to ensure ethically sound practice, which is set out in the General Social Care Council (GSCC) Code of Practice (2001). Butler (2002) argued that "the ethical foundation for a code of research ethics for social care work research is to be derived from the ethics of social care itself".

The Department of Health's Research Governance Framework (2005) for health and social care also seeks to promote improvements in research quality across the board. It sets out key standards across five domains, and lists some core elements of quality research in health and social care. The key standards reach across the following five domains:

- Ethics;
- Science;
- Information;
- Health, safety and employment;
- Finance and intellectual property.

The key elements of a quality research culture listed in the framework are:

- Respect for participants' dignity, rights, safety and well-being;
- Valuing diversity within society;
- Personal and scientific integrity;
- Leadership;
- Honesty;
- Accountability;
- Openness;
- Clear and supportive management.

It is important that the ethical approach is the golden thread through the study and even the findings (Shaw, 2008), which Orme and Shemmings (2010) stated should be "morally active". The ethical standards established by the Social Care Research Ethics Committee, i.e. dignity, rights, safety and wellbeing of the people who take

part, were also embedded into this research. With the support of a reflective learning process, ethical considerations remained paramount.

These principles were adopted in this study and safeguards, as described by Creswell (2003), were applied to protect participants' rights. The research objective was clearly articulated verbally and in writing for the participants, including how the data was to be used (Appendix C – Research Information Sheet). The board of trustees and chief executive were also written to in order to seek authorisation for this study (Appendix D) and written agreement was received (Appendix E):

1. Participants were written to (Appendix F – Letters to Participants) and they provided consent to take part in the study (Appendix G – Consent Form);

2. Verbatim transcriptions, written interpretations and reports were made available to the participants for comment, and their feedback was sought (Appendix H – Semi Structured Interviews and Appendix I – Focus Group Transcripts). In order to support the governance of the semi-structured interview and focus group process, a protocol checklist assisted in the ethical promotion of the study (Appendix J – Interview Protocol Checklist and Appendix K – Focus Group Checklist);

3. The final decision regarding the participants' anonymity rested with the participants for comment. The participants had the final decision in censoring any information in the transcripts that may have jeopardised their anonymity;

4. The participants were made aware that they had the right to withdraw from the study at any point.

4.4 Epistemological Background of Situational Analysis

Situational analysis was first presented by Glaser and Strauss (1967) as a popular epistemologically sound approach to qualitative analysis called 'grounded theory'. Glaser and Strauss provided a research tool that promised to make qualitative research more analytical and systematic. Its roots were embedded in sociology, symbolic interactionism and the pragmatist philosophy, and it offered an empirical approach to the study of social life. Clarke (2005) moved the theory further, pushing grounded theory around the postmodern turn by introducing a new approach to analysis within the boundaries of grounded theory, known today as situational analysis.

Situational analysis is a framework for professional practice and research and it offers a set of principles so that work is evidence-based, ecological, constructive and collaborative. It offers researchers to draw together studies of discourse and agency, context, history and structure etc. to analyse complex situations. This methodology was chosen as it provides direction for this research and it is versatile in supporting

the diverse community at individual and systems levels. A purist approach was not taken to situational analysis; however, the versatility of such an approach allowed for various techniques to be adopted that took into account the changeability of the various ecological systems. Situational analysis therefore permitted and supported the synthesis of Bronfenbrenner's Ecology System Theory. This methodological approach engenders collaboration between participants at every level, it is supported by legitimate evidence at every point of the process and offers better reflexive research. Finally, it supports multi-views that involve the integration of large amounts of information, reflecting the many views of the participants on complex situations and encompassing the interpretivist paradigm.

Clarke highlights a radically differing conceptual framework from Strauss's theory and replaces action-centred "basic social process" with Strauss's situation-centred "social worlds/arenas/negotiations" framework. This demonstrates that Clarke did not condemn this historical ideology, but rather built upon and extended Strauss's work. What Clarke hoped to achieve here was more reflexivity, uncertainty, modesty and representation of contradictions, continuing to explicitly follow Strauss's vision. Clarke's argument for this is based on the fact that its roots are in pragmatism and it anticipated the postmodern turn. The assumption that "truth is enacted" (Strauss and Corbin, 1994) by the researchers' social and material contexts must, as these contexts change over time, be seen as processual, which is thoroughly modern: instead of applying a Cartesian style of reasoning that doubts the truth of everything, pragmatism teaches us to focus on the practical consequences in situations where truth is said to be found.

Situational analysis is deeply rooted in epistemologies and ontologies of symbolic interactionism, defining the situation explicitly. According to Clarke, a situation is a moment where people produce common meanings of symbols interaction.

Due to the complexities of symbolic interactionism, researchers are able to draw from other concepts in their attempt to make things explicit. Riessman (2002) discussed this: "Some fancy epistemological footwork is required…borrowing or combining methods forces investigators to confront troublesome philosophical issues and to educate readers about them". We may not be able to resolve these issues; however, bringing them to the forefront of discussion is an important part of the reflexive work within the research.

More emphasis was placed on micro process analysis, whereas Strauss was particularly interested in the macro phenomena, or what is known as social world/arenas, which will be discussed shortly, however, the theoretical perspective could be traced back to the pragmatist belief that the way things are done by groups enables us to make claims on collective ways of thinking. Strauss believed it was vital

to analyse how social structures operate as 'conditions' and which social processes occur, which Clarke (2005) then extended within social world and arena mapping.

Charmaz (2000) criticised Strauss and Glaser, however, stating their data as distance experts, suggesting they keep an objective distance to the field. Both Clarke and Charmaz found fault that, in grounded theory the field is made smooth and pure; the results are presented as objective and rational and it tends to represent a field with merely a few codes. Charmaz and Clarke were both seeking to create a kind of grounded theory that avoids these positivist underpinnings to form a revised, more open-ended practice of grounded theory that stresses its emergent, constructivist elements. This led to differing results, with Charmaz citing constructionist grounded theory with the aim of developing interpretive understandings. However, Clarke (2005) took this one step further with the aim of emphasising positionalities, partialities, complications, instabilities etc. This is what she meant by postmodernism.

The second element of situational analysis concerns taking the non-human in the situation explicitly into account. This has been done for years using grounded theory, but it has not been undertaken without methodological reflexivity (Clarke and Star, 2008). First, introduced by Foucault (1973), *The Order of Things* opened up the consideration of an array of things, as well as the person. From this emerged actor-network theory, which offered an explicit theoretical and methodological account of the non-human. Research into actor-networks requires the analytic task to follow leaders, offering descriptions of what they do whilst including the production of and interaction with the non-human.

This approach fits well with the research questions in this study as this theoretical approach allows for understanding the interrelationships, allies and translation of information in processes, practices and policies. It also allows the research to follow the non-human object as it migrates through the ecology system as it links both human and non-human actors with heterogeneous components, e.g. values, attitudes, resources etc., as outlined in the ecology system of the methodological research framework.

An example of this can be synthesised between Bronfenbrenner's Ecology Systems Theory and non-human actants. The exo system where participants are not involved in situations that may still affect them can cause conceptual ruptures through which participants will see the world afresh and different. Taking things for granted in practice and procedure will be ruptured by new non-human elements such as policy change, which will cause a shift in perspective, migrating throughout the ecology system. These invisible non-human forces may not be the catalyst, but they are rendered explicit and primary.

The third and final push by Clarke involved rethinking the relationship between 'condition' and 'situation' within social worlds and arena mapping. Whilst focusing

on micro systems, Clarke destabilised Strauss's distinction by arguing that conditions of the situation are in the situation itself. Clarke stated, "there is no such thing as context". Strauss and Corbin, however, focused on context regarding individuals, organisations, regions etc., as attached to modernist reasoning and separable from the world. There are indeed some analytical advantages to distinguishing between poles such as the micro and the macro, individual and society, etc.; however, according to Clarke, the fundamental question needs to consider how these conditions appear and make themselves felt as consequential inside the empirical situation under examination.

4.4.1 Situational mapping

Situational maps were used because they lay out the major human, non-human discursive and other elements in the research situation of inquiry and provoke analysis of relationships among them. As Clarke argued, "the conditions of the situation are in the situation and there is no such thing as context. The fundamental assumption here is that everything in the situation both constitutes and affects everything else in the situation and can lead to the conditions of possibility" (Foucault, 1975). The major human and non-human aspects are presented and mutually consequential.

Although in the course of this study the situational map did not have everything included from the situation, it did at least start teasing out the broad and complex nature of the situation itself and also helped to establish ideas, concepts, discourse and cultural matters of the situation. Getting to grips with this research through adopting situational mapping helped and steered this work. The following ordered situation map (Table 8) offered insight:

Table 8: Ordered Situational Mapping

Individual Human Elements/Actors	**Collective Human Elements/Actors**	**Non-human Elements/ Actants**
▪ Autism practitioners/support staff ▪ Service managers and leaders ▪ Clinical professionals e.g. behaviour teams, psychiatrists, hospital staff etc. ▪ Families/carers	▪ Professional organisations e.g. local authorities, Hospitals ▪ Government ▪ Organisational Supports e.g. BILD, skills for care/health etc. ▪ Manager/staff interactions and influences	▪ Cost of provision and support to person with autism ▪ Technical resources ▪ Codes of practice ▪ Database for epidemiology
Discursive Constructions of Individual and/or Collective Human Actors	**Discursive Constructions of Nonhuman Actants**	**Implicated/Silent Actors/Actants**
▪ Unavailable behaviour	▪ Managing crisis in	▪ People with autism do not

specialists ▪ Expectations from NHS staff are unrealistic with unskilled staff teams ▪ People with autism need responsive treatment to avoid sectioning	community settings due to over prescribed hospitals and NHS targets to reduce admissions ▪ Socio-economic situation ▪ Unfit environments	have a voice ▪ Parents, families, carers
Political/Economic Elements	**Sociocultural/Symbolic Elements**	**Temporal Elements**
▪ Reduced funding in social care ▪ Funding/salaries of social care staff is low ▪ Policy unrest concerning social care ▪ Lack of policy guidance on procedure and governance ▪ Too much focus on what went wrong rather than learning to put right	▪ Should be skilled/professional work, but not seen as this e.g. currently unskilled workforce. Lacks cohesion. ▪ Societal perception is poor and suspicious of all social care provision ▪ Expectations of care differ greatly	▪ Time spent with people with autism is reduced due to administration tasks ▪ Overtime and burnout issues ▪ Recruitment shortage ▪ Capabilities and competencies
Spatial Elements	**Major Issues/Debates** **(usually contested)**	**Related Discourses (historical, narrative, and/or visual)**
▪ Incompatibility in homes for people with autism ▪ Homes not fit for purpose e.g. too small, no break out facilities ▪ Care giving more invisible and at arm's length	▪ Staffing ratios and perception of what support levels people require ▪ Level of service not meeting statutory needs ▪ Support – clinical practice of autism ▪ Re-structuring of services ▪ Invisible institution and cultures	▪ Crisis in social care ▪ Serious case reviews publicised, causing societal attitudes to become negative and suspicious of all social care services ▪ Practitioner past history/experiences ▪ Quality of life outcomes
Other Key Elements		
▪ Emotions of the work e.g. stress and burnout ▪ Emotions of people with autism e.g. frustration at being restricted		

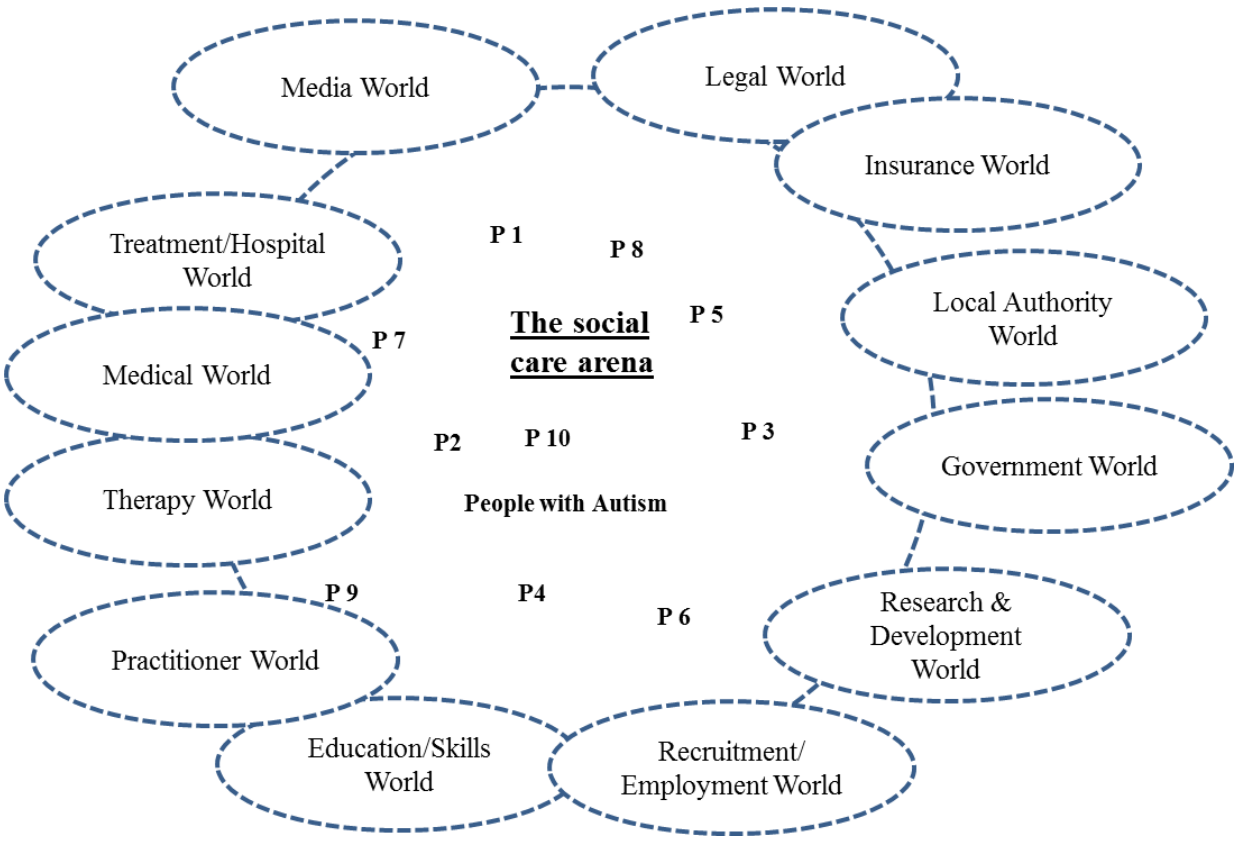
Memo-ing at the end of the mapping session helped to draw out new insights and returning to this ordered situational map was equally important as it helped the analysis and fluidity of relationships and repositioning of the situation as the research progressed.

4.4.2 Social worlds/arena maps

Social worlds/arenas maps lay out the collective actors, key non-human elements and the arena(s) of commitment and discourse within which they are engaged in ongoing negotiations, in particular the meso level interpretations of the situations.

Social worlds are the principle affiliative mechanisms through which people organise social life. Insofar as it meaningfully exists, society as a whole, then, can be conceptualised as consisting of layered mosaics of social worlds and arenas. Arenas are defined as the interaction by social worlds around issues – where actions concerning those are being debated, fought out, negotiated, manipulated, and even coerced within and among the social worlds. Looking at Figure 5 we can see an array of social worlds in the social care arena. Many of these worlds are medical, government and educational worlds with numerous professionals and communities of practice merging into the social care arena. People with autism are present, but are not collective actors and they live in between practitioners, doctors, nurses etc. They are, however, implicated actors, discursively constructed by many other worlds within their own arena.

Figure 5: Social World Arena Mapping



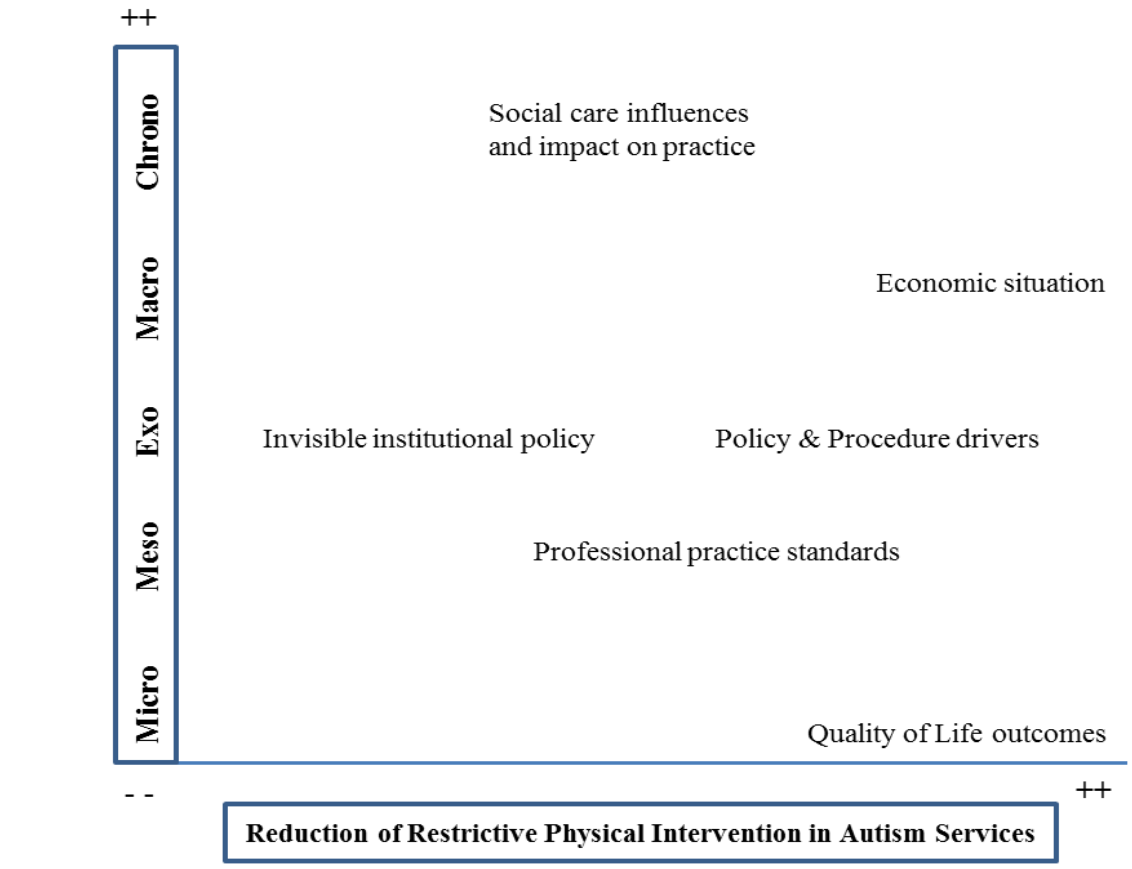
Social world mapping helped this study to see that there are a number of very powerful and influential worlds interacting with the social care arena that could be considered as constraining and differentially enabling the situated actions of people with autism. Figure 5 demonstrates the 'squeeze' placed upon the social care arena; it helped to illustrate how and why the complexities are at play within the ecology system and it assisted in drawing out the broader scope of the research.

4.4.3 Positional maps

Positional mapping assisted in elucidating from the data what the basic and not always contested issues were in the situation. These different positions were then dimensionally placed on a positional map, however, this soon became complicated from an empirical world perspective and required further analysis, which meant that the positions wove back and forth until saturation occurred.

To summarise the positional map, there are two main axes and when analysing I tried to lay out the axes in terms of 'more versus less'; this was used alongside situational and social world mapping. Figure 6 focuses on the reduction of restrictive physical intervention in relation to the major components of the ecology system. The positionality of social care influences within the chrono system impacts the reduction of restrictive practices and may well have influenced the economic situation and the interrelationships between the remaining systems. Translation loss has therefore been a major implication as a result of societal attitudes and influences.

Figure 6: Positional Mapping



As with social world mapping, this map was referred to on many occasions with regular re-positioning until saturation occurred.

4.4.4 Discourse analysis

In the work of Jaworski and Coupland (1999), discourse analysis is essentially the analysis of language in use. This is extended to visual images, symbols, non-human things/material cultural objects and other forms of communication. All of these modes are culturally and historically located and open to discourse analysis.

In Allen's and Hardin (2001) publication, *Discourse Analysis and the Epidemiology of Meaning*, hermeneutically speaking, the 'meaning' is in the interaction between interpreter and text. The association of one set of signifiers with another is never fixed or determined, but bounded. Allen takes this further by arguing that multiple interpretations are required, but some more strongly than others.

Allen and Hardin describe vocabularies of our different workplaces as ‘natural’, often forgetting how long we have worked to acquire them. These vocabularies can be markedly different, even in workplaces that have a strong interface with one another. Outsiders of these workplaces may therefore have trouble understanding and knowing how to act within them. This can cause us to be at odds with them and even cause conflict.

Discourse analysis is much more than depiction, illustration, portrayal and image. The theoretical framing of discourse analysis sits within the assumptions of an era that are both inscribed and embedded in texts. These texts require analysis to be part of webs or systems and their significance exposed. Language systems are characterised by an era or situation, therefore analysis can extrapolate text in relationships to illuminate the structure of meaning.

Discourse analysis was part of this study’s methodology as texts constituted a major source of evidence for grounding claims about the social structures, relationships, interrelationships and processes.

4.4.5 Reflexivity

Reflexivity is also key to this research. In this part, I will first address the problematic pretence that as a researcher, one should be considered invisible from a grounded theory viewpoint. This was particularly manifested and extended by numerous researcher’s should be ‘blank slates’ when entering new research. He argued that researcher’s should ‘not know’ as they approach data.

In contrast to this argument, and from a situational analysis perspective, Clarke asserts that a person can’t help but come to the research not knowing the situation. As discussed in 4.2.4, my positionality brings an embedded stance due to both the role I occupy in the organisation and my position as researcher; I am naturally affected already by my own extensive experience.

This raises an interesting debate due to the potential for personal bias and intellectual narcissism, which exceeds reflexivity and therefore focuses more on ‘us’ rather than ‘them’. Unlike Strauss and Corbin (1998), who had no intention of conveying experience as data, my belief is that knowledge is valuable of for, rather than a potential hindrance to, this study. The multiplicity of perspectives, adopting a more Straussian approach to analysis of data, can mitigate the imbalance of any researcher over egged reflexivity. More objectivity is therefore achieved.

Conversely, greater reflexivity is required due to my positionality and hierarchy. People will naturally position individuals, like it or not, and a certain amount of power is apportioned to those undertaking research. This, of course, is more likely within my position, therefore reflexivity is needed that enhances the capacity to

address this. This can also mean that participants find themselves positioned tacitly, if not explicitly, for example, managers supporting the underdog, i.e. support staff and the controversy of their situation. This can offer greater visibility of the situation, whilst also embellishing the situation falsely. Reflexivity is therefore vital in understanding and seeking the truth.

4.5 Mixed Methods

In order to achieve the research objectives, this study employed a mixed method approach, which provided methodological triangulation to the research. A consensus definition of this approach is:

> Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the purpose of breadth and depth of understanding and corroboration (Johnson et al., 2007).

From a pragmatic viewpoint, mixed methods is seen as legitimate to the extent that it solves research problems better than either approach employed in isolation. Using mixed methods to corroborate findings, which may also overlap at times, offers methodological triangulation. This is often used in social care practice and will provide greater trustworthiness of the findings (Golafshani, 2003). This can also offer added value through 'expansion' and 'complementarity'; to ensure completeness of the research this added value offers the ability to increase the range and breadth of this enquiry and it facilitates the interpretative paradigm.

This method offered the opportunity to illuminate the experiences of leaders, autism practitioners and people with autism. There were two phases to this:

- **Phase 1:** Qualitative methods – semi-structured interviews with leaders of the organisation were undertaken in order to capture the impact that a PBS framework has on both leadership and practice. Emergent theory was then taken from these interviews and applied to focus groups in order to capture how this framework has been translated into practice. Returning to situational mapping/social worlds/arenas and positional mapping helped to make sense of messy situations.

- **Phase 2:** Quantitative methods – a questionnaire was used to operationalise the data. Using a Linkert scale, key themed response domains were then measured and analysed against the methodological framework in Figure 7. A mixed method design therefore strengthened both quantitative and qualitative research approaches. Alone, quantitative and qualitative methods have some strength, but

more benefits are realised when they are brought together. This point is further highlighted by Connelly (2009), who wrote, "the goal of mixed methods research is to draw on the strengths and minimise the weaknesses of both types of research".

4.6 Data Collection Methods

Adopting a situational analysis for this study allowed a variety of data collection methods to be used. This was generated in heterogeneous ways, e.g. semi-structured interviews and focus groups etc. Consideration was taken of the kinds of data collection methods that realistically could be achieved; this included considering the adequacy and trustworthiness of the materials gathered and analysed.

4.6.1 Semi-structured interviews

Regional directors and service managers were interviewed at the commencement of the research and towards its end in order to capture the impact the PBS Framework has had on both leadership and practice. This method is seen to be a good way of accessing participants' perceptions, meanings, definitions of situations and constructions of reality. Interviews are a widely accepted technique for conducting a social inquiry and they are a familiar method in social care practice.

A qualitative interview has been developed to obtain deep, rich data utilising an investigational perspective (Creswell, 2007). In interviews, the different epistemological positions of the individuals engaged in the process emerge through meaningful interactions, and knowledge is constructed in collaboration with the interviewer. Thus, the nature of the language style, the words I use as the researcher and those of the participants, shape the nature of the data collected; this impacts how interpretations of the data are made using discourse analysis approaches and allows me to engage deeply in the interview process and in the participants' experiences in order to develop shared understanding. Qualitative interviewing helped to understand how custom and practice was created and maintained while exploring specific social and political phenomena. This elicited depth and detail in findings.

Rubin and Rubin (2005) outlined three issues that were considered to ensure that the participants being interviewed and myself as the researcher were able to successfully understand each other: first, understanding of the culture, which influences how the interview is heard and understood; second, interviewers are not neutral actors, rather they are participants in an interview process and their emotions and cultural understanding will impact on the interview; and third, the purpose of the interview is to hear what the participants are saying, giving them a public voice.

A practical disadvantage of interviews is that they can be time consuming and may require a large amount of travelling. Gaining access to participants can be slow, and transcribing can be time and cost consuming; careful planning and organisation was required to mitigate this. Semi-structured interviews, however, are more flexible, easy to use and inexpensive. Their broad focus gives sufficient flexibility that new concepts and ideas can emerge. The advantages of this approach are that it empowers stakeholders, whilst still defining a set procedure.

Reflexivity supported collaborative discussions to develop with each participant. By gently guiding the conversation, leading the interviewee through the ecology system stages in order to support the research objectives helped immensely. In semi-structured interviews, I acknowledged the social aspects of the research process as being important. Such interviews challenge conventional assumptions of research in that the interview is described "as a setting for data gathering" by the researcher on the researched. In this view, we became partners and co-constructors of knowledge.

The interview questions were developed in line with the research objectives, whilst being influenced by the PBS philosophy and the literature review. The Interview Protocol Checklist was used to assist me in the major issues to be addressed and to promote a consistent approach to each interview. I also developed new questions in the course of the interviews in order to explore the participants' perspectives in unique ways. The second interview became more focused as a result of returning to situational analysis techniques.

4.6.2 Focus Groups

As a method of data collection, focus groups seem to have grown in popularity in social care. This method allowed this study to tap into human and non-human tendencies, as outlined earlier in situational analysis. Attitudes and perceptions relating to concepts of PBS and autism practice, training programs and practice standards developed in part through interaction with participants to create the framework. Thus, focus groups directly influenced the PBS Framework, helped explore and clarify values and assisted in shaping and framing practice.

Essentially, a focus group is an interview style designed for small groups. In this work, it involved a group of autism practitioners discussing and commenting on particular areas drawn from the semi-structured interviews with leaders. This allowed practitioners to interact and share their views and to understand their community of practice better.

Focus groups have strength in being naturalistic. I was able to listen to discussions, whilst also identifying emotions, ironies, contradictions and tensions. This enabled me to learn or confirm not just the facts, but also the meaning behind the facts, thus producing insight from a humanistic point of view (Anderson and Braud, 2011).

The hallmark of these focus groups was the capacity to capture the group dynamics of these practitioners through explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in the group. Interpersonal characteristics within a group, however, can influence the cohesiveness and compatibility, which may lead to group conformity, leadership emergence and interpersonal conflict. Forsyth (2014) highlights that members of groups influence and are influenced by one another. Understanding the dynamics of the group therefore created greater homogeneity and increased willingness to communicate (Forsyth, 2014).

Focus groups can be relatively structured, with specific questions asked of each group member, or very un-structured, depending on the research purpose. For the purpose of these focus groups, the following structure was adopted:

1. Definition of the 'research question'.
2. Identification of the sampling frame using situational analysis techniques.
3. Researcher as moderator.
4. Generation of focus group protocol.
5. Recruiting of the sample participants within service areas (being aware of dynamics).
6. Conducting the focus group.
7. Analysis and interpretation of data.
8. Writing up the findings and returning to situational analysis techniques.
9. Decision making and actions to be taken.
10. Consideration of the impact of practice and evolution of the PBS Framework.
11. Reflexivity.

The environmental factors also need to be considered as they can influence rapport and participation, such as spatial and interpersonal distance, use of physical layout and room size. The number of participants in a focus group was also considered. Contemporary groups involve 8 to 12 individuals as experience has shown that smaller groups may have certain dominant members and any more than 12 participants may be difficult to manage.

Four regional focus groups of between 8 to 12 practitioners were undertaken and all participants were from the regional director/service manager autism specialist provisions and they knew each other well. The discussions lasted two hours. The focus groups involved semi-structured and open-ended questions, which had been developed following the interviews with directors and service managers. This was to test out the leaders and managers' findings, how this had impacted on practice and to explore what had been lost in translation. The same process was adopted for the second interviews with leaders and managers and focus groups towards the end of the study. This method was useful in clarifying responses, probing for further detail and

incorporating follow up questions in order to further investigate and assess the impact of the PBS Practice Framework on practice.

By promoting participant comparison and contrasting views and experiences, I was able to gain insights into the consensus and diversity of perspectives and discourses (Forsyth, 2014). From an interpretative perspective, I was able to check participants' interpretations of the findings.

The focus groups have a number of strengths for this study:

- I was able to interact directly with the participants and this gave me the opportunity for clarification and follow up questions.
- They afforded the opportunity to observe non-verbal responses, which is a practice requirement of PBS that I was familiar with.
- Offered large and rich amounts of data in participants' own words and were flexible to deliver.

Adopting this approach helped establish emergent theory. This was further enriched by constant comparison and analysis of findings, which was then modified within the interview phase to further enrich the theory.

For the purpose of this research, participants were provided with information prior to the focus group outlining the role of the researcher, professional ground rules and making an assessment at the start of the session regarding interpersonal and group dynamics, all of which was essential. All focus group sessions were transcribed for further analysis rather than using detailed notes so as not to affect the flow of the focus groups. Additional observational data was also used; in particular, non-verbal communication with participants and preplanning of analysis was considered essential.

Analysis of the content examined the meaning of responses and their particular implications for the study. Krippendorf (2013) defined this as "a research technique for making replicable and valid inferences from text to the contexts of their use". Throughout each stage of the focus group structure, every effort was made to interpret content.

4.6.3 Questionnaires

The questionnaire is primarily a measurement instrument. Its main purpose in this research was to operationalise the user's data into a format that assesses how dependable the findings are, rather than solely providing statistical measurement. The concepts of "reality" must be operationalised in a way that enables the subject matter specialists and users to carry out the necessary analysis, which the questionnaire designer can implement into the questionnaire and the respondents can understand

and answer properly. Hence, the design of questionnaires must primarily take into account the statistical requirements of data users. The measurement, wording, structure and layout in this case made allowance for the nature and characteristics of the respondent population.

This questionnaire design started with a review of the existing literature, contextualising my experience and also discussions with experts in the field. As a result, the questionnaires were divided into key themed areas:

- Specific knowledge;
- Attitudes and experiences;
- Competencies;
- Practice standards;
- Service outcomes;
- Monitoring practice performance.

This mixed method approach was used as it had the advantage of taking it to a wider audience to gauge how the chrono, macro, exo and meso analysis levels were impacting on the micro level of the community of practice. From a qualitative perspective, it was a familiar tool to social care practitioners.

The questionnaire (Appendix M) was highly structured with all questions being numbered to ensure they are asked in the right order and all responses were coded to facilitate data entry and analysis. Each participant was given a unique reference number to ensure anonymity. Comparisons were made following the re-test of the questionnaire to capture the impact this research has had on practice.

The Likert scale was used as the response category in this study due to its familiarity in social care. In order to standardise the response, participants in the focus group sessions were asked to complete the questionnaire and consider the questions and responses associated with the past month's experience. Following a contextualised approach helps participants to make sense of the research being studied.

Each Likert response generated an item score, e.g. 'strongly disagree' = 0; 'disagree' = 1 etc. The scores were then transformed to produce dimension scores of the corresponding scale. This method provided a representative perspective baseline, which was then re-tested towards the end of the research to capture practice impact. Although there is no appropriate sample size for any research, questionnaires were provided to 48 participants during the focus group sessions. This ensured a proportionate perspective of the wider autism practitioner workforce across a large geographical area. Questionnaires were incorporated into the focus groups to increase response rates because questionnaires have the disadvantage of low response rates.

Statistical techniques were then used to compare participants' responses to the questionnaire items and analyse this. The scoring item was totalled and presented by the number of participants and the percentage against each response. This was re-tested towards the end of the research and scores were presented and compared to capture the emergent theory and impact.

4.7 Selecting Participants

This investigation is a single case study of a large UK national social care organisation supporting people with autism. It takes an interpretative approach to examining the impact that a PBS training framework can have on the capabilities and competences of an autism specific community of practice.

The participation criteria required leaders, managers and practitioners to be directly involved in delivering autism specific services. The scope of participants involved were:

Table 9: Scope of Participants

Position	Overview of Service	No. of people with autism	No. of autism practitioners
Director A	North East – 56 services in total, of which 39 are autism specific	117	327
Service Manager A	North East – day to day management of 7 services	21	57
Percentage in Participant Groups		**18%**	**17%**
Director B	North West – 48 services in total, of which 22 are autism specific	73	308
Service Manager B	North West – day to day management of 5 services	10	43
Percentage in Participant Groups		**14%**	**14%**
Director C	Midlands – 74 services in total, of which 44 are autism specific	176	528
Service Manager C	Midlands – day to day management of 18 services	89	224
Percentage in Participant Groups		**51%**	**42%**
Director D	South West – 23 services in total, of which 9 are autism specific	37	93
Service Manager D	South West – day to day management of 4 services	9	31
Percentage in Participant Groups		**24%**	**33%**

Focus Group A	North East – complex needs autism and high functional Asperger syndrome		8-12
Focus Group B	North West – complex autism		8-12
Focus Group C	Midlands – complex needs autism and co-morbid conditions		8-12
Focus Group D	South East – high functioning autism and Asperger syndrome specialist service		8-12

Although PBS involves a person-centred approach, no participants were people with autism. The focus in the research was to develop a holistic practice framework for leaders, managers and autism practitioners that would be implemented within autism services. Only autism specific services were identified in order to satisfy the scope of the research aims and questions.

Firstly, a letter (Appendix F) outlining the study and its purpose was sent out to potential participants via their directors. This process also allowed directors to discuss this study within their own service areas, to consider how this would contribute to their community of practice and to consider which services and teams would benefit most. It was also made clear to directors that it was important to ensure a broad cross section of staff at all levels to explore the research objectives. Table 4 provides an overview of the participants across the social care structure; pseudonyms were provided for each director and service manager, whilst other participants received a reference number.

4.8 Data Analysis

Data analysis is about making sense of the data that has been collected during the research process; in this case the interview transcripts, focus groups, questionnaires and observations. The data were analysed according to the stages recommended by Smith et al. (2009), outlined below:

Table 10: Data Analysis Research Structure

Stage	Title	Description
1	*Reading and re-reading*	Immersing self in the original data by reading the interview transcripts several times. Record responses to the interview.

		Reflective records made.
2	*Initial noting*	Initial level of analysis describing the content, commenting on the language used, such as key words, phrases or explanations, and conceptual coding. Aim to produce a comprehensive and detailed set of notes about interviews and focus groups.
3	*Developing emergent themes*	Aim at this stage is to organise and interpret the data. Analysing discrete chunks of transcript. Analysing the notes and reflective records, mapping the interrelationships, connections and patterns. Aim to produce evidence of leadership and practice key components in order to 'bridge the gap'.
		The process of mapping how the themes relate to each other and identifying their impact on the community of practice. Use situational analysis strategies.
4	*Searching for connections across emergent themes*	Repeat the process with the remaining interview transcripts and focus groups.
		This stage involves laying out the themes for each transcript and focus group notes and looking for patterns and connections.
	Moving to the next case	
5	*Looking for*	

	patterns across participant cases	
6		

Data analysis is an iterative procedure requiring close engagement with the data so that the researcher is able to gain an 'insider perspective' (Reid, Flowers and Larkin, 2005). Each participant was treated as an individual and analysed following stages 1-4 outlined in Table 2. The analysis was a cyclical process in which it was possible to move between the stages, rather than following a linear process.

The primary goal within this data analysis was to create substantive categories that emerged in the participants' responses in focal areas of a PBS practice framework. Themes were identified and analysed with regards to their relevance and importance. The coding of the text into substantive categories was about grouping of ideas into thematic units. The process of reiteration was used by following the Table 2 structure.

Reflexivity prompted recall of experiences as the data was analysed in order to recall the context in which certain responses by the participants were made. The data analysis began early and continued at each phase, which helped narrow the study to reach the thematic units. This also helped with checking interpretations and drawing conclusions.

Thematic analysis (Braun and Clarke, 2006) was used due to its flexible approach, which arises from not being tied to a particular theoretical model. It has, however, been criticised as a poorly demarcated approach that underpins all other qualitative methods. Nonetheless, Braun and Clarke maintain that it is an independent method of analysis in its own right and it aims to identify, analyse and report patterns and themes within data.

4.9 The Research Procedure

There were three direct contacts with the participants. An initial visit was undertaken to each of the directors, service managers and teams involved in the study. This was an opportunity to discuss the study and provide participants with the research information sheet and consent form. The aim of the initial visit was to build a rapport with participants and to gain some familiarity with the context of their services. This also enabled a description of each director and service manager to be developed.

After the initial visit, all participant groups completed the consent form and returned these, which initiated formal recruitment for the research process. All directors and

service managers were then interviewed, with interviews lasting approximately 30 minutes. Each interview was taped. The length of the interview was, to some extent, flexible depending on the issues being discussed. These interviews focused on analysis of the ecology systems within the community of practice, whilst also evaluating the perceptions of what was being practiced at the micro level. After each interview was transcribed, the transcripts were given to the participants and their feedback was sought and confirmed as accurate. This allowed for the drawing of conclusions and checking content validity.

Following on from the leaders and managers' first interview, focus groups were conducted in the regional areas, each lasting two hours, to allow every participant the opportunity to be involved and discuss their experiences of supporting people with autism. Questionnaires were also used to capture staffs' competencies in order to inform the research aim.

A holistic PBS training programme was then introduced for leaders, managers and autism practitioners to attend. This programme consisted of autism specific topics covering:

- Positive behaviour support core theory (including legislation and de-escalation strategies);
- Autism awareness;
- Co-existing conditions and autism (how this can affect a person's behaviour);
- Managing autism services;
- PBS awareness;
- Mindfulness
- Incident management recording and reporting;
- Post incident management de-briefing;
- Positive and proactive risk management;
- Leadership in PBS;
- Mental capacity and deprivation of liberties for people with autism;
- PBS intensive practitioner five day programme.

Courses initially were delivered generically so that participants could participate in the broad range of PBS topics, and then a range were delivered on a bespoke referral basis for staff who were supporting complex individuals. This was done over a ten-month period.

Towards the end of the research, directors and service managers received a final interview. Focus group participants also received a final group session. The same process was followed and then transcripts, observational notes, questionnaires and reflective records were triangulated and analysed in order to compare findings and evaluate impact on practice.

Practitioners then completed four service users' profile reports, which were anonymised before being received and chosen by the director and service manager. These highlighted quality of life before and after the PBS training framework. Directors received a summative report of the research findings and the proposed impact in terms of critical reflexivity on their own practice.

4.10 Authenticity and Trustworthiness

Within qualitative research, authenticity is an important issue. In establishing authenticity, I sought reassurances that both the conduct and evaluation of research was genuine in terms of participants' lived experiences and also the political and social implications. This was discussed at length during my university supervisions. The main body of this study is qualitative, focusing on understanding the meaning of the phenomena as described by the research participants (Silverman, 2013). Large numbers of participants are not necessary when it is understood that the goal of the research is to provide a foundation for future studies. The study therefore shifted largely away from reliability and validity and concerned itself more with qualitative research being worthwhile and thinking about the impact it would have on the community of practice.

The important component here is that of trustworthiness so that it will be of benefit to autism practitioners and in turn make a positive contribution to enhancing quality of life for people with autism. These rich, experiential findings generate true authentic understanding of practitioners, managers and leaders.

This study was also concerned with transferability; the study does not make broad claims, but instead invites readers to make connections between the research findings, PBS Framework and their own experiences and to apply the framework within the wider social care community. It is therefore important to ensure a rich description of the current environment within the findings of this report so readers will be more confident in transferring it to other situations.

4.11 Conclusions

In this chapter I have highlighted the professional doctorate research framework (Figure 4), which provides a visual understanding of the methodological approach undertaken. An interpretative paradigm was chosen and the rationale explained and analysed alongside other research assumptions. My positionality as a researcher was explored and considered following a review of the literature and the advantages and disadvantages of my embedded stance. Ethics was illuminated, navigating the reader to relevant appendices.

The epistemological background of situational analysis was discussed at length and particularly focused on the work of Clarke (2005), although a critical analysis of other academic literature was also offered. Situational analysis was then broken down and discussed with respect to situational mapping, social world mapping/arena mapping and positional maps, whilst being synthesised using Bronfenbrenner's Ecology Systems Theory. Discourse analysis and reflexivity was briefly considered to take account of multiple interpretations, translational loss and researcher positionality.

A mixed method approach was discussed, along with the rationale for the data collection methods adopted. To conclude this chapter, I addressed the selection of participants, data analysis process, procedure and authenticity and trustworthiness.

CHAPTER 5: RESEARCH FINDINGS

5.1 Introduction

Adopting Bronfenbrenner's Ecology Systems Theory as the structure for this chapter, each research question from Figure 2 (Research Aims and Questions Framework) offers findings of the situation prior to any PBS practice framework being implemented. Situational analysis methods will illuminate the findings and help establish deeper understanding in order to support the final chapters of this thesis. The structure of this chapter will allow the reader to see how the data answers the research questions and how the data rests on the literature framework.

5.2 Micro System Situation

Understanding the situation of the micro system will provide this research with empirical findings on practitioners' immediate environment in which they are practicing. As the theory suggests, the practitioners are not just recipients of the experiences; they also contribute to constructing the situation. Understanding how the situational criteria in Table 11 occurs and how practitioners, leaders and managers interact and react in their environment will have an effect on the lives of people with autism.

Identifying the instability and unpredictability of the micro system will assist in the emergence of practice indicators so that capabilities and competencies can be promoted and supported and quality of life outcomes are achieved.

Table 11: Situational Analysis - Micro System

Situational Analysis - Micro System		
Situation Criteria	**Research Questions**	**Data Sources**
▪ Economic situation of the environment ▪ Workforce cohesiveness ▪ Management/staff social interactions & influence ▪ Competencies/ Capabilities in PBS practice ▪ Quality of Life outcomes	1. What is the key criteria practice benchmark indictors for developing a PBS framework that will enhance the competencies and capabilities of autism practitioners so that autism practices are predictable and offer stability for people with autism? 2. What are the quality of life outcomes from implementing a PBS Practice Framework for people with autism and the autism practitioners?	Primary Data: ▪ Focus Groups ▪ Semi structured interviews ▪ Questionnaires Secondary Data: ▪ Previous research ▪ Government reports ▪ Website information

5.2.1 Research question 1: what are the key criteria practice benchmark indictors for developing a PBS framework that will enhance the competencies and capabilities of autism practitioners so that autism practices are predictable and offer stability to people with autism?

The literature emphasises how PBS training can be part of the wider systems change, which can be synthesised with Bronfenbrenner's Theory due to the ecological systems being intertwined. Here, I explore the situation from various perspectives in the semi-structured interviews:

> **Service Manager (Jim):** *I find it hard to understand how to apply the regulations surrounding behaviour in a way that is practical. CQC often comment that we need to evidence better but they don't offer advice on how to do this so we are left to interpret this ourselves.*

> **Director (Emma):** *Behaviour is such a complex area to cover (and to manage) and we don't concentrate on this enough in our training and certainly don't link autism with this. We have lots of training in physical intervention but nothing on how to write behaviour plans and reports – what's the standard there? Is there one? I don't think even policy goes into the detail we need. We don't have any training or standards on de-briefing. I think this is a crucial area for our staff to learn and understand why incidents happen.*

These statements are examples of Mansell's (1994) research findings, which continue in his later research of 2007 and 2010: that managers and leaders should have full command of their role. There is a clear fragmentation of this here in terms of regulation, theory and practice. The whole systems approach is also not considered and behaviour training is taught in isolation of other concepts and philosophies. This will cause a disconnection between managers and practitioners and instability is caused as competencies and capabilities will not only damage practice, but also cause social tension between management and practitioners due to the system being fragmented. We will see later what the impact is of this on the system levels.

Hygiene factors, adopting Hertzberg's Motivation Theory (1959), also suggests that leaders and managers do not have the necessary competencies, which will influence their own motivation and capacity to be confidently visible within the service. The language discourse suggests frustration due to lack of skills in leaders and managers. This will impact on the micro environment at a quality of life level as working conditions will diminish due to lack of good practice indicators in settings and decision making not being consistent with philosophical approaches. We can draw comparisons from this with Woodbridge and Fulford's (2004) values-based medicine, Fact and Values Model. Valued reasoning occurs when practitioners understand the value base and the evidence that comes with it, however, when the philosophical value base of PBS is not understood, then leaders will not acknowledge or see the

'right' evidence. It can be argued further that they will not respond appropriately when the evidence is incorrect, which will therefore have a direct and negative influence on quality of life. Instability is further complicated by leaders' decision making lacking transparency and clarity of thought. This theoretical perspective offers a unique and deeper viewpoint of the situation.

There are several points to make about these leaders' comments when considering the design and content of the PBS Framework:

1. The regulations do not provide the leaders with the practical guidance required to ensure full compliance. CQC are not permitted to give advice, therefore leaders are left to decide for themselves.
2. Training tends to focus more on 'challenging behaviour', rather than positive behaviour support. The organisation also has separate courses for autism and behaviour and there is no forum to discuss the two components (9.2 Portfolio) in relation to a person they support. Understanding how autism affects a person might well answer why they may present with behaviours of concern. Often practitioners see these as two separate issues.
3. The organisation does not offer any training on behaviour assessments (4.3 Portfolio) and writing PBS plans. This will account for some of the challenges raised earlier in the literature.
4. The organisational training programme is impressive, but too generic and not person-centred (9.7 Portfolio).

The impact of this can be considered in the following practitioner statement:

> **Focus Group A:** *We do lots of training, from mandatory to more specialised, such as autism, but it never really hits the spot. It's great sitting in a classroom learning about autism but it seems so different when you see it through your own eyes in real time. We could also do with training on incident recording. We constantly get pulled up for this not being right, but nobody has trained us so that's to be expected.*

Applying discourse analysis to this statement can extrapolate text in relationship to identifying the structure of meaning. Theory suggests that assumptions are embedded in an era or situation. In Focus Group A, the following use of language offers an insight into the micro environment: "*We constantly get pulled up for not being right*". This use of language demonstrates tension and conflict between practitioners and managers due to competencies and capabilities not being consistent with the task. Bronfenbrenner's Ecology Systems Theory suggests that practitioners are not just recipients in terms of a management directive, but are contributing to constructing the environment. This will affect workforce cohesiveness, in particular relationships and behaviours, and it is clearly causing tensions within the environment, which will result in indirect instability for people with autism. This will also influence the meso

system and sub-cultures will form. We will see the extent of this later in the system levels.

Providing capable incident recording systems therefore requires a workforce development programme (9.2 Portfolio). This current deficiency has a causal effect on the quality of life of people with autism as practitioners are constructing a negative environment and interrelationships will fracture as information gets lost in translation. We see evidence of this in practitioner questionnaires, 51% stating (Appendix R-17) they disagree that incident recording and reporting is clear and objective and 96% (R-16) considering people with autism to be restricted in their skills and independence as a result of behaviour.

Capable and competent incident recording and reporting would certainly improve the stability in people's lives, as reflective practice would be promoted here and it would assist in learning and improving practice. This would influence workforce cohesion and produce more consistent responses in practice. Considering this from a person-centred and ethical value base needs to be included in practice development so that practitioners appreciate this concept. Although capabilities are important, they clearly need to sit within a larger system change framework with training being fit for purpose and interlinked throughout practice so that systems change can truly be achieved.

The organisation offers a limited range of courses on autism and positive behaviour support, which can therefore limit the competency of workforce practice. The relevance of the training is also another factor in how it translates into practice and the bridge between theory and practice causes knowledge to be lost as practitioners are only provided with generic training. This will affect the social interactions between management and practitioners and the decision making process will become more autocratic. As Action Centred Leadership Theory suggests, there can be a disconnection between staff, management and leaders in the above statement; this discourse is evident in the Focus Group A findings.

As the Ecology Systems Theory suggests the micro and meso systems are inextricably linked and it is worthy of mention that workforce social influences and cohesiveness are affected by the meso value led decisions. Seedhouse (2005) explains that exposing these values, drive and inform decision making which is a similar viewpoint to Woodbridge and Fulford (2004).

Evidence is much more powerful as it is visible, which Seedhouse suggests, however, value-led decisions are invisible and often lead to decisions being made that are not congruent with the value-led approach, as we have seen in these findings. Considering this from a quality of life perspective, person-centred values become restricted, thus decisions are not based on an ethical philosophy or framework. Morris (2005) highlighted the lack of choice and control in children's lives in care and although

policy may embed this philosophy, practice is lagging behind at the micro level. The practice indicators in this case are not just the practical application of PBS and autism practice, but responding to the implicit components of 'philosophy in practice', as well as the explicit practice indicators. These initial findings indicate a whole systems approach to practice indicators with an infrastructure of linked systems thinking with practice standards embedded from exo policy in order to repair competencies and capabilities.

The above has moved my thinking beyond the initial practice framework and developed a deep understanding of what the framework needs to achieve within a cohesive ecology system, understanding that the philosophical foundations are central to achieving this. Careful consideration therefore needs to be taken due to the interrelationships the systems have with each other, which I will explain in relation to the following research questions.

By coding the data and adopting messy social world mapping (Appendix N and P), Figure 7 starts to see some of this situation forming in the early stages and it has been cross referenced with the completed portfolio reference numbers to indicate where they now sit within the framework.

Figure 7: Social World/Arena Mapping of Practice Benchmark Indicators

This mapping exercise continued until all findings were considered and no further changes were required. We will see in the following questions how each of these

areas are often interconnected with the others, therefore influencing other ecology system levels to offer stability of the micro environment.

5.2.2 Research question 2: what are the quality of life outcomes from implementing a PBS practice framework for people with autism and the autism practitioners?

Research by Beadle-Brown, Murphy and DiTerlizzi (2008) indicated that people with autism and behaviours of concern independently contribute to lower quality of life outcomes. Due to their vulnerability, the actions of others from the meso environment can directly affect the person's micro environment, as suggested by Bronfenbrenner. Mansell's (2007) government report identified how quality of life can be affected by the values and attitudes of others around the person. This requires further exploration.

In research question 1 (5.2.1), I have highlighted that a multi-dimensional approach is required to address competencies, capabilities and workforce cohesion. I now extend this to quality of life outcomes and consider the impact that the meso system has on quality of life.

The following statement demonstrates values, attitudes and norms and how they can affect and impact the micro level:

> **Focus Group A:** *When staff are in positive moods this tends to rub off on the service users. The service users can really pick up on the moods of staff when they are feeling down, tired or negative. There are times when we do get disheartened, especially when it comes to not having the resources for person-centred approaches. Due to the way funding is working, people really don't have true person-centred support.*

We can consider this statement from a psychological contract perspective and focus on organisational and behaviour theory by Argyris and Schein (2004) and from a PBS perspective by Huckshorn (2005). Organisationally, we see a disconnection between policy and community of practice norms, beliefs, values and attitudes, which are directly impacting on people with autism, but also on the practitioners themselves. This demonstrates that practitioners are constructing their environment. The emergence of poor quality of life from a value-led perspective was well documented at Winterbourne View (Department of Health, 2012) and the slippery slope to abuse and creating toxic environments began with a lack of leadership and management of organisational values and attitudes. This shows the inextricable link between the meso and micro levels. Therefore, to consider one without the other would be dangerous.

From a PBS viewpoint, Huckshorn considered the psychological contract by proposing developing relationships between leaders, managers and practitioners. The statement above highlights a discourse in perceptual understanding of the micro

environment and a dangerous 'group think' approach being created. Huckshorn argues that engaging in discussions to create mutual understanding will help emergent expectations of service user quality of life goals, clear planning and practice objectives and eventual workforce cohesiveness. However, the findings above demonstrate a disconnection between management and practitioners; therefore maintaining the integrity of this mutual understanding is lost.

The use of language here also identifies the economic situation and their understanding being one of 'restriction'. From question 1, lack of visible leadership and drive does demonstrate that the psychological contract is further fragmented and will only deepen. Social relationships in discursive interaction can illuminate this point further. The rights of people with autism can either be transformed or denied due to the values and attitudes of social care staff based on their perceived power in the discourse of disability. Without sound policy drivers from the exo system to promote a value-led training programme, this discourse will continue to occur.

Both Carr (2007) and Mansell (2010) addressed how attitudes can create practice difficulties in promoting quality of life. This was prevalent in all focus groups and can be best explained in the following statement:

> **Focus Group B:** *When we try new things that go wrong we go back to our old ways. When we don't understand something that is not answered for months we start to make judgments, lose objectivity and become unmotivated.*

There is little evidence here of knowledge exchange and working together in cohesive collaboration. The exo policy is not driving values and attitudes into the micro practice to encourage person-centeredness so that quality of life is promoted. It is, however, affecting the person from a micro perspective, resulting in a lack of reflective practice, returning to old restrictive ways and people with autism becoming frustrated with lack of opportunity, choice and control, as described in the policy driver, 'Valuing People Strategy' (2001, 2009).

We can see this lack of reflection in Table 12, with 79% of participants stating that their attitudes positively affect quality of life outcomes for people with autism.

Table 12: Focus Group Questionnaire Outcomes on Attitudes and Experiences

Question	*Strongly disagree* *(1)*	*Disagree* *(2)*	*Neutral* *(3)*	*Agree* *(4)*	*Strongly agree* *(5)*
My attitude (and those of my team) positively affects outcomes, e.g. quality of			20.83%	35.42%	43.75%

life, for service users.					
I am able to use my experiences positively to improve my practice when supporting people who challenge me.		39.58%	27.08%	22.92%	10.42%
There is an attitude of reducing restrictive practices.		16.67%	22.91%	50%	10.42%

It is interesting to note that these findings are inconsistent with Seedhouse (2005). In Table 12, based on Seedhouse's theory, we should see more visible evidence. In this case the reduction of restrictive practices, such as restraint, is a powerful and visible source of evidence. The findings at this initial stage suggest otherwise and actually contradict practitioners' perspective that their attitudes positively improve practice and quality of life. If this were the case, their attitudes would reduce restrictive practices as the literature suggests. The lack of relevant training and reflective practice may account for this anomaly and may also support my argument earlier that lack of understanding of the philosophical principles may promote lack of acknowledgement when evidence is presented.

Quality of life outcomes are both implicit and explicit, which is possibly not understood here and supports Seedhouse's theory. The more implicit components of 'Valuing People' (2001), such as choice, control, independence, opportunity etc., lack evidence in these findings, particularly in reducing restrictive practices, and they may well be considered a restraint issue rather than a broader phenomenon.

A further impression of these findings may demonstrate discourse between practitioner ideological views, as opposed to the person with autism. This directly challenges person-centred and PBS philosophy of creating better lives for people we support. Wolfensberger, Thomas and Caruso (1996) identified that some ideology is not explicit, such as people with autism living ordinary lives. The findings demonstrate that the power imbalance can cause practitioners to make decisions that are not value-led and are thus more restrictive due to not understanding the implicit quality of life factors of the 'Valuing People' strategy or the foundations of person-centred philosophy.

We currently see limited evidence-based findings of quality of life outcomes for both people with autism and their practitioners due to a lack of PBS approaches and training. However, what is evident is a greater focus on practitioner attitudes from a meso viewpoint than on the micro quality of life of service users, which demonstrates a staff-led approach rather than person-centred approaches being implemented.

5.3 Meso System Situation

Social worlds/arena maps are key to meso analysis and are based on social action. This involves social beings who are committed to social worlds and their participation in those worlds, through activities which simultaneously create and are constituted through discourses. Adopting situational 'meso' analysis will help in illuminating collective action directly and empirically. Social worlds/arena mapping helps this research to see the participants of this study acting as individuals and members of the social world. This will help to identify regimes of practice, social formations and the discourses produced and circulated within services.

Figure 5 (page 82) captures the complex social world arena within social care, each one with a set of values, attitudes, expectations, standards and power. In the micro situation values, attitudes and norms are discussed from the perspective of how they affect quality of life outcomes. Here I will discuss how policy impacts practice and how it shapes these values and attitudes, as outlined in Table 13.

Table 13: Situational Analysis - Meso System

Situational Analysis - Meso System		
Situation Criteria	**Research Questions**	**Data Sources**
▪ Community of practice norms, values & attitudes ▪ Professional practice standards (skills set) ▪ Management approaches to transparency & communicating the PBS message	3. How does organisational policy impact on autism & PBS practice; in particular how are values, attitudes and norms created when translating policy into practice?	Primary Data: ▪ Focus Groups ▪ Semi structured interviews ▪ Questionnaires ▪ Life history experience – related discourse Secondary Data: ▪ Previous research ▪ Government reports ▪ Website information

5.3.1 Research question 3: how does organisational policy impact autism and PBS practice; in particular, how are values, attitudes and norms created when translating policy into practice?

The aim of policy is often ambitious and the dissemination and implementation of the policy is not always taken into account or led by leaders and managers, and is evident in this situation. There was disparity between what leaders and practitioners said about how policy is communicated and disseminated:

> **Semi Structured Interview (Leaders):** *All policies are discussed in our managers meetings and then disseminated by the managers. This way I can talk*

managers through policies first. It's really important that managers understand these policies because they are communicating this to their teams.

With the reality at practice level being:

> **Focus Group B (Practitioners)*:*** *Not really sure that it is actually communicated. We use a system called Citrix where all information such as policies is kept. We normally get an email saying that there has been a policy update. What is meant to happen is our manager discusses the policy in our team meetings. Sometimes we might not have a meeting for months. It's normally because we are short staffed so we go months without looking at policies. There's really not enough time to read them.*

The 'lost in translation' definition provided in 3.12 highlights the rhetoric and reality of the phenomena in these statements. Leaders are taking a linear approach to dissemination and no concept is considered in relation to how this will be interpreted and communicated by managers to practitioners, nor does this take into consideration the constraints the teams are under in terms of staffing. As a result, only 4.17% (Appendix R) of the focus group practitioners indicated in their questionnaires that they consider the policy to help them understand how to support people with autism. A combined disagreement of 58.33% stated that the policy offered no support to aid their understanding.

The dissemination of policy is clearly not robustly managed in these two conflicting statements; however, practitioners' interpretation of this was consistent through all focus groups. Leaders' interpretation was more inconsistent, which might be attributed to lack of visibility within teams, as discussed earlier, therefore assumptions are inconsistent with reality. It is worth exploring how policy is disseminated and communicated to the workforce as this is critical for knowledge translation, as suggested by leadership and management theory.

The questionnaire findings identified that over 50% of participants did not find the policy useful or support their understanding of policy or practice. This will not lead to the creation of new knowledge and nor does it direct and guide practices and standards. Figure 4 – Professional Doctorate Research Framework also identifies the importance of leadership and how this can bridge the gap between leadership and practice. Organisational policy from the exo system will influence knowledge application and bridge this gap at the meso level. We see in these findings that the lack of transparent communication approaches, which should be driven by leaders and managers, is actually causing the reverse effect within the meso system.

Knowledge structures will then be reformed with values, attitudes and norms distorted from those set out in the actual policy. Ordered situational mapping outlined in 4.4.1 demonstrates how policy in this case does not drive values and attitudes and can cause

unrest and instability at the macro and micro level. The meso system is therefore vital in constructing and supporting the other systems.

The leaders and managers demonstrated in their responses that there is no clear definitive understanding of policy dissemination. There was, however, consistent evidence of placing large responsibility on managers and leaders either not engaging with their workforce or consideration that policy needed to be actively led by them. Examples of this include:

> **Semi Structured Interviews (Leaders):** *I don't think it's my job to do this. I like to distribute some of this leadership to my managers.*

And:

> *Where there is any change in government policy or within my organisation I discuss this at our managers meetings, however, I do expect managers to attend Social Care Governance meetings because this is where it sits.*

These statements indicate that leaders do not consider how this approach to dissemination could mean that the workforce lose vital knowledge. Leaders' responsibilities were considered complete once they had transferred knowledge to managers and multiple dissemination pathways were not evident in the findings even though leaders were aware that their approach was 'traditional'. Therefore, policy is diluted and can break down a cohesive approach to practice, and dynamics within relationships between leaders and practitioners can be affected.

We can consider this further by applying leadership and management theory to the phenomenon. The central component of Action Centred Leadership Theory is that workforce interpretation of policy is consistent with organisational vision and vision is transferred and translated into meso practice. Leaders' statements do evidence that there is a disconnection between them and policy. Without leaders being visible and role-modelling, the policy will affect the entire ecology system (Bronfenbrenner, 1979).

Tensions can become apparent between leaders and practitioners, thus increasing the difficulty in implementation and translation of the policy into practice. This is evident in the following practitioner statements:

> **Focus Group B:** *We often question the strategies, as they don't make sense so staff don't use them. The plans don't tell us how to implement the strategies. They are often inconsistent with autism needs.*

> **Focus Group C:** *The PBS plans are not explained to us and sometimes we know the person better than the manager. Interventions don't meet the needs of the service user. This is often left up to our own judgement. We are unsure how*

to implement interventions so there are inconsistencies. We continue just doing the same things because managers often don't know the answer either.

These two statements continue the theme of non-engagement between leaders and practitioners and therefore directly impact on policy in practice. This is potentially dangerous as values, attitudes and norms can be re-shaped if nobody is driving this, as Winterbourne and other serious case reviews have shown us. We now see the signs of pressures placed on practitioners. This directly relates back to Mansell (2007), where he acknowledged that lack of practice leadership is due to no strategic focus of policy.

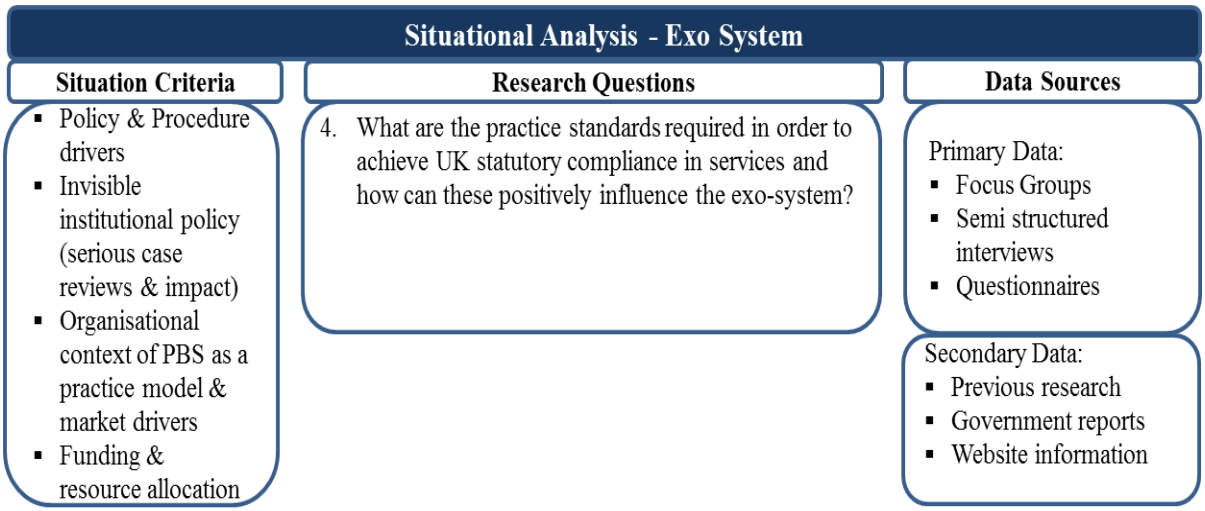
We can also relate this phenomenon with Dunham and Pierce's (1989) Leadership Process Model. Leaders need to take charge, direct policy and be visible in order to monitor performance. The converse of this is a service/organisation that lacks vision, standards and capabilities. The context of the system lacks maintenance and becomes sterile with practice indicators/standards reducing due to unmotivated staff who then practice in a way that is inconsistent with person-centred approaches and become restrictive in their thinking. This could affect long-term practice and distort experiences and the future recruitment resource pool.

Dunham and Pierce argue that the outcomes, if not formed and shaped correctly, may be inconsistent with the aims and objectives of practice. The discourse can often be a result of inconsistent values, attitudes and norms in practice. A further outcome to consider is a reduction in trust and respect between leaders and practitioners, with morale being affected, all of which are the ingredients of a toxic environment.

5.4 Exo System Situation

The exo system is an extension of the meso system and, as Bronfenbrenner (1979) suggests, it embraces social structures, which don't contain the person directly but can impinge both directly and indirectly on people. The situation outlined in Table 14 will also affect the meso and micro systems in terms of placing pressure on practitioners, which may result in detrimental consequences for the quality of life of people with autism. It can also jeopardise practice standards and the successful implementation of compliance. The prolific effect of reduced funding resources, policy changes and the impact this can have on practice requires exploration.

Table 14: Situational Analysis - Exo System



5.4.1 Research question 4: what are the required practice standards to achieve UK statutory compliance in services and how can these positively influence the exo-system?

In order to consider the practice standards I will first outline the exo system influences within the current situation. Government policy is slowly influencing the exo system, as the research suggests, however, this is being seriously affected by the economic pressures placed on local authorities and service providers. This was uncovered in the following semi-structured interview:

> **Director (Debbie):** *The decisions we have to make become less person-centred and more about how to make ends meet. Local authority financial cuts are having a huge strain on us, however, the expectations of delivery have gone up.*

Bronfenbrenner (1977) argued that government changes in policy and the economic situation without full understanding can cause anxiety, confusion and breakdowns between leaders and practitioners. This will influence the service users' micro system and affect relationships between leaders and practitioners, which we have seen. From an ontological perspective, leaders, managers and practitioners will socially re-construct this situation and, rather than being part of the solution, be contributors to the problem. The exo system is therefore influencing and reducing innovation, creativity in new practices and approaches and 'corner cutting' of practice standards is being seen and, rather than problem solving, we see a self-fulfilling prophecy and a contribution to the discourse. When policy is weak there is no guidance or governance of philosophic values and practices.

The impact of serious case reviews has been immense in terms of exo system influence, some of which is less explicit but can be illuminated through discourse analysis:

> **Service Manager (Graham):** *Winterbourne has shaped national policy and damaged the reputation of social care. Winterbourne has clouded professionals' judgements*.

And:

> **Director (Sam):** *Policy focuses too much on what has gone wrong rather than how we put it right*.

And:

> **Service Manager (Ray):** *There is a lot of new guidance, but the community is still left interpreting it with mixed understanding*.

The theoretical framing of discourse sits within the assumptions of the Winterbourne era and is embedded in the above texts (Allen and Hardin, 2001). These statements demonstrate the invisible institutional culture that is being constructed by the community. They highlight that there is a lack of practical guidance to offer support and direction.

Ray's statement demonstrates a lack of understanding of policy, which will ultimately affect practice standards. Policy level decision making, if interpreted wrongly, will cause conflict and relationship breakdown at a micro level. We can see evidence of this within the initial questionnaires (Appendix R). Practitioners were asked to respond to the following statement: "The PBS policy provides me with an understanding of how to support people with autism who may challenge." Practitioners' aggregate findings were 96% either neutral or disagreed with this statement. This demonstrates strongly that policy is not influencing practice in a positive way and it offers no guidance on implementation on practice.

The literature on both international and national policy indicates that policy is the catalyst for change, however, there is a further argument to be made. 'Valuing People' (2001, 2009), 'Fulfilling Promises' (2001), the 'Bamford Report' (2005) etc. all indicated a drive towards personalisation, choice, empowerment and independence, however, decisions made at the micro level as a result of these policy drivers may not be consistent with the policy message at the exo level, therefore the policy needs to be explicit in what standards are to be achieved. Communicating the government message is clearly an essential component of the PBS Practice Framework, however, these findings also suggest that there needs to be practice standards for leaders to ensure this message is not lost in translation. This would therefore influence the exo, meso and micro systems and help develop ownership over policy.

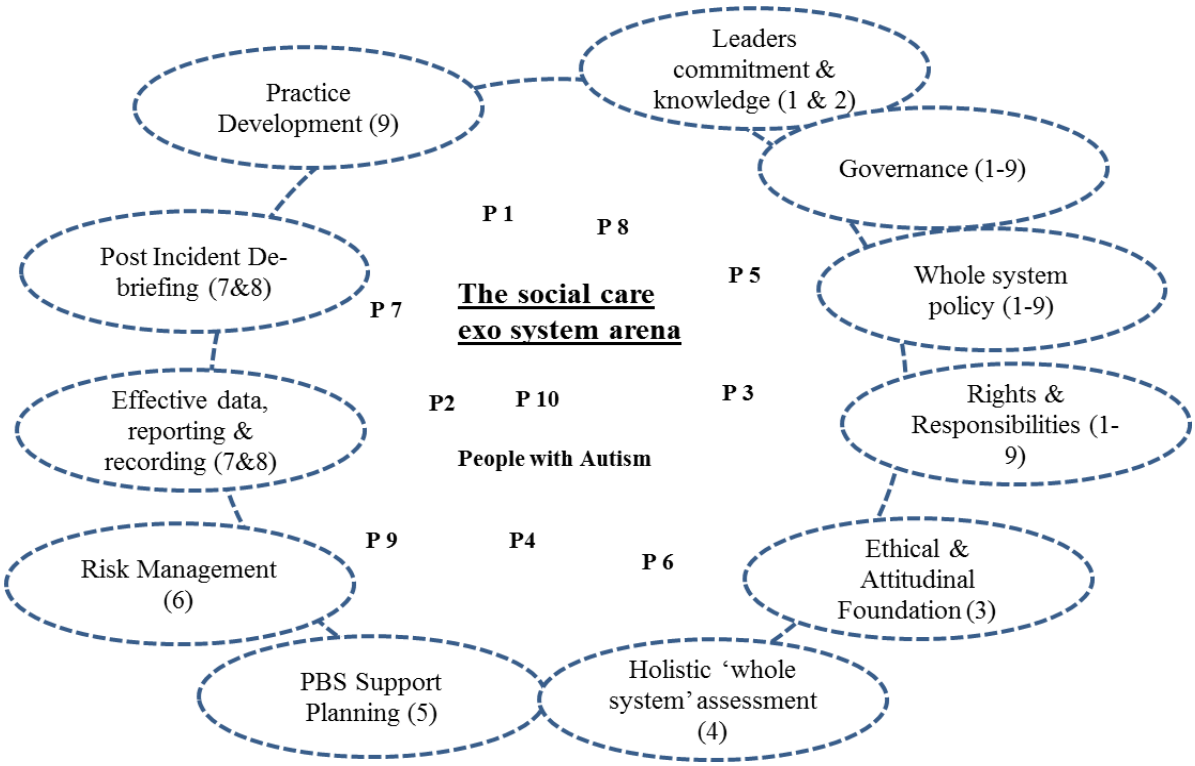
Further examples can be drawn from the findings from focus group sessions and questionnaire responses where practitioners are not directly involved in designing policy and practice standards, which can be seen in the statements concerning the practice procedures that have been designed and interpreted from policy. These highlight the conflict between the exo, meso and micro systems:

- *The paperwork doesn't help us understand why behaviour has occurred* (43%);
- *We don't get adequate de-briefs or only get them when something big happens* (87%);
- *The strategies are inconsistent with autism* (67%);
- *The assessment is normally done before the service user moves in but we've never seen any of that information*.

It is vital that any exo decisions regarding the PBS Framework reflect the situation above and that policy offers a whole systems approach, as Bronfenbrenner (1979) suggests. Social world/arena mapping (Figure 7) was adopted on numerous occasions until saturation was reached in order to identify what practice benchmark standards for compliance were required and what would be a conceptual fit with the practice indicators.

The findings outlined in Appendix N and P from semi-structured interviews and focus groups were grouped together into categories and highlighted the practice standards for compliance, which also navigate to their locations in the final portfolio. These findings were triangulated with the government statutory guidance – 'Positive and Proactive Care, 2014' and considered as a contextual fit.

Figure 8: Social World/Arena Exo System PBS Practice Standards



The inductive approach adopted here has allowed this research to identify (from Figure 7) the fundamental practice standards framed within the social world arena map. The initial emergent knowledge shows that policy is integrated as a whole system throughout the entire framework, as well as governance, rights and responsibilities. Further work is required to ensure that these standards are interconnected with the practice indicators, which the following ecology systems will offer.

5.5 Macro System Situation

The macro system is described as the overarching pattern of micro, meso and exo systems and will support this research in avoiding any translational loss of information and understanding. It focuses on the belief systems, body of knowledge and cultures that are embedded in each of the broader systems, as Table 15 summarises. Exploring the macro environment will identify what leaders, managers and practitioners' interpretations are of the situation and what discourse is illuminated. This will equally help to uncover what practice benchmark indicators/standards are required to re-address and reframe these interpretations in today's community of practice so that the PBS Framework can positively influence the exo system. Adopting macro systems theory continues the framing and reframing exercise within situational analysis for a final robust practice framework.

Table 15: Situational Analysis - Macro System

Situational Analysis – Macro System		
Situation Criteria	**Research Questions**	**Data Sources**
▪ Culture & sub-cultures of the environment ▪ Economic situation ▪ Political (international & National) situation ▪ Leadership & Governance situation	5. How do the interactions and interconnectedness of different policy factors within a PBS context affect practice and what are the dynamics at play that can cause a 'lost in translation phenomena'? 6. What are the leadership and governance practices required to promote open and transparent cultures and can help to positively shape the economic and political environment?	Primary Data: ▪ Focus Groups ▪ Semi structured interviews ▪ Questionnaires ▪ Life history experience – related discourse Secondary Data: ▪ Previous research ▪ Government reports ▪ Website information

5.5.1 Research question 5: how do the interactions and interconnectedness of different policy factors within a PBS context affect practice and what are the dynamics at play that can cause a 'lost in translation' phenomenon?

A common theme that leaders reported was a lack of policy knowledge in the literature. A range of generic social care leadership skills appeared to be more evident than specialising specifically in PBS and/or autism. Leaders were able to outline some of these pressures:

> **Semi Structured Interview (Director – Debbie):** *I know in my services we are challenged by behaviour because we don't understand the reasons why it is happening. Person-centred understanding helps to some extent, but after that we are left scratching our heads and at times referring to specialists outside of the organisation.*

> **Semi Structured Interview (Director – Sam):** *I don't really understand the process of behaviour assessment other than the basics and as I am not an autism specialist I would struggle with knowing what interventions to use. We probably get this wrong a lot of the time, even with our good intentions.*

In his seminal research, Mansell (1994) highlighted this as a problem, stating that practice leadership should be the primary concern, rather than administration, or in this case generic leadership skills. All leaders demonstrated that regulation and compliance took priority over their own continuous professional development, therefore policy understanding is lacking. Leaders expect all practitioners to attend the relevant courses specific to their services; however, they don't themselves attend.

This can lead to discourse of the macro level and thus affect the exo, meso and micro systems in turn. The literature shows us that governance is strongest when control, coordination and regulation is evident in the macro ecology system. Leaders are not

linking the macro situation to the micro, therefore the functional logic of the organisational policy is affected and this can cause major discourse. The lack of policy understanding is also applicable here as leaders do not understand how to implement the policy in practice. They lack the policy and political understanding from the exo level and their practical knowledge and application lacks theory of autism and behaviour so decision making may be inaccurate.

From a governance systems theory perspective, this major discourse can then dissolve into conflicting groups, individuals and systems. This can lead to power struggles within the internal and external systems and therefore cause further economic pressures and more restrictions placed on providers by government. Ordered situation mapping was used here to help extrapolate the complexities of the situation from different policy factors and what dynamics were at play, as in Table 16.

Table 16: Ordered Situational Mapping of Different Policy Factors Synthesised with Findings

Individual Human Elements/Actors	Collective Human Elements/Actors	Nonhuman Elements Actants
▪ Autism Practitioners/Support Staff. ▪ Service Managers & Leaders. ▪ Local Authority commissioners & contract team. ▪ CQC Inspectors.	▪ Government. ▪ Manager/staff interactions & influences. ▪ Health Professionals e.g. OT's, SALT, Pyschiatrists etc.	▪ Re-structuring and re-design of services. ▪ Cost sustainment. ▪ Sustaining occupancy. ▪ Satisfaction that policy has been delivered appropriately and consistently for service users – satisfaction?
Discursive Constructions of Individual and/or collective Human Actors	**Discursive Constructions of Nonhuman Actants**	**Implicated/Silent Actors/Actants**
▪ Practitioner imagery. ▪ Complex and demanding service users. ▪ Behaviour professionals are unavailable. ▪ Managers and Leaders not visible and lack answers. ▪ Autism Leads not available.	▪ Unfit environments. ▪ Economic situation with lack of resources. ▪ Standardisation of policy implementation.	▪ People with autism.
Political/Economic Elements	**Sociocultural/Symbolic Elements**	**Temporal Elements**
▪ Reduced funding in social care. ▪ Funding/salaries of social care staff is low. ▪ Policy unrest concerning social care. ▪ Lack of policy guidance on procedure & governance. ▪ Too much focus on what went wrong rather than learning to put right.	▪ Cultures and sub-cultures are inconsistent with policy message. ▪ Not seen as skilled profession yet policy requires skilled staff. ▪ Variations on expectations between CQC, Local Authorities and Contract Teams.	▪ Overtime and burnout issues. ▪ Recruitment shortage. ▪ Capabilities and competencies
Spatial Elements	**Major Issues/Debates (usually contested)**	**Related Discourses (Historical, Narrative, and/or Visual**
▪ Incompatibility in homes for people with autism. ▪ Homes not fit for purpose e.g. too small, no break out facilities. ▪ Care giving more invisible and at arm's length so less governance of policy/practice.	▪ Staffing ratios and perception of what support levels people require. ▪ Level of service not meeting statutory needs. ▪ Support – practice of autism. ▪ Re-structuring of services. ▪ Invisible Institution & cultures.	▪ Crisis in social care. ▪ Serious case reviews publicised, causing societal attitudes to become negative and suspicious of all social care services. ▪ Practitioner past history/experiences.

Table 16 offers an array of information to reflect upon, therefore I have chosen some salient points based upon my own experiences within the situation, which are aligned with the literature (Clarke, 2005).

- The density and complexity within the sociocultural/symbolic elements raises variation in regulations and contractual standards. The expectations of the governing bodies, e.g. CQC and local authority contract teams, can often lead to conflict and disparity in monitoring and reviewing. Different professional interactions with policies can lead to different outcome requirements, which change every time policies are audited. The readers' interpretations can often be influenced by current situations. This can lead to a discourse of confusion over practice and vital information being lost and not understood.

- The terminology used in the situation map identifies many situational complexities and more about the fragmented situation in which social care lies, as described by Mansell in his last publication 'Raising Our Sights' (2010). The lack of focus on people with autism and more emphasis placed upon the economic and political situation thus directly demonstrates the lack of impact that the 'Valuing People Strategy' (2001, 2009) has had within the community and for people with autism themselves. 75% (Appendix P Code: 15/20) of practitioners responding stated this is a significant factor. This is similar to my findings within the micro system. The Think Autism Strategy (2014), whilst advocating developing assessment pathways, specialist local authority appointed leads and autism friendly environments, in reality is lacking due to economic resources. Interconnectedness of policy is lost due to this strategy not being a statutory requirement.

- All of the human interaction is constituted in and through the properties and conditions of the broader situation. For example, consider the structural elements of government, leaders, managers and health professionals. These should all form a cohesive structure that allows us to make structural and re-design decisions that are fit for purpose and informed by policy and assessment of need. The major and related discourse demonstrates here that we are in a constant state of re-structure due to crisis situations and serious case reviews. The spatial effects of unfit environments contribute to this, all of which impacts on the inter-connectedness of policy. Information will, no doubt, be affected by this and lost in the multiplicity of communication and in the bias reasoning of each professional's expectations within their own community.

- Appendix P offers further insight into the challenges of implementing policies correctly to ensure connected philosophy and ethical practice. Participants responded by an overwhelming 100% (Code: 27) that they do not get time to read policies, largely due to a lack of staffing. As a result, values and attitudes see an impact at 75% (Code: 26). Policy information is clearly not just lost in poor dissemination, but also lost due to an unmotivated and directionless workforce.

5.5.2 Research question 6: what are the leadership and governance practices required to promote open and transparent cultures, which can help to positively shape the economic and political environment?

Paley's (2012) 'Framework for Reducing Restrictive Practices and Promoting Positive Behaviour' identified a clear governance structure that required modelling by leaders and managers. In the same year, the Department of Health published 'Positive and Proactive Care', outlining a similar governance approach that providers could follow. Considering the macro system and the issue of governance, the following semi-structured interviews with leaders highlight the situation:

> **Director (Debbie):** *Our behaviour policy is poorly written and leaves gaps in how to apply in practice.*
>
> **Service Manager (Graham):** *Policies are distributed without any guidance.*
>
> **Service Manager (Jim):** *Staff focus on behaviour and don't respond well to it so the quality of the service is affected.*

We can consider these statements from a discourse perspective. Policy is a constructivist approach that helps to reveal the social, political, cultural and practice factors lying within the policy topic. The ideas and meanings become constructed and governance starts to be formed from the conception of the policy design through an interpretative approach, where interpretation of policy lacks transparency and clarity statements such as those above can lead to critical discourse of the macro system.

We see in the use of language, such as "poorly written" and "gaps in how to apply", that opinions and perceptions have been formed. We also see that policy dissemination is not considered part of governance and therefore it lacks leadership and importance. These are clearly important practices to be promoted.

Finally, we see a statement from Jim, who is describing the exo, meso and micro system when the macro system is weakened. The vision and intent of the policy in this statement is lost due to lack of leadership. Cultures and sub-cultures will have limited direction and practices will diminish. Jim highlights that in the current situation leaders have lost focus on the policy and as a result they are possibly also losing focus at the micro level. We see this on a number of occasions in responses from practitioners. The following response, although only one focus group highlighted this, makes for an interesting discussion:

> **Focus Group B:** *When we don't understand something that is not answered for months, we start to make judgements.*

This statement demonstrates that leaders and managers are either not visible or they are unable to answer these dilemmas. What previous findings have captured is that

both are highly likely to be the case. The impact on practice at a governance level is also worrying, with a 100% (Appendix P: Code 62) response rate stating that reporting and recording does not help to understand the service user better as it is often not completed. Knowledge transfer does not take place due to 75% (Code: 65) stating that the paperwork does not help them understand behaviour and 50% (Code: 66) stating that de-briefs only happen when significant incidents occur.

The challenge that the leaders face in this situation is to integrate the various social actors and the complexity of relations between the components of the system, as Figure 8 suggests, which requires them to have the skills and be confident in leading and managing this. The findings identified fragmentation of policy governance at a micro level, which demonstrates how the macro system is flawed from an integration viewpoint:

> **Director (Allison):** *Managers are overwhelmed by numbers of incident reports to monitor and don't get time to check them all. There is also a delay in reporting and monitoring. This means we are unable to respond and, more importantly, learn from incidents.*

This statement demonstrates a lack of governance from two perspectives: first, to monitor and safeguard vulnerable people; and second, policy does not inform practice or feedback loop into policy. We see that knowledge translation and transference is weakened due to the governance arrangements put in place and I have already highlighted the lack of training that practitioners receive at the micro level, which adds further complexities.

The reporting template being used was cumbersome and not fit for purpose. Managers reported a lack of time to complete due to a reduction in support hours with service users. This highlights a further weakness in knowledge translation due to the economic situation. The mechanisms and methods used had not been reviewed for many years and were not a contextual fit with the current situation, which influenced attitudes and cultures. Although not part of this study, it is a strong possibility that reports would become biased and not objective.

There was no evidence that leaders had considered the notion of governance and knowledge translation. However, what Allison's statement does indicate is potential conflict and disagreement, which will feed uncertainty and multiple interpretations of reality being constructed. There was no evidence that knowledge translation represented a process of developing what had been learned to reach new knowledge. Three of the four focus groups (B, C and D) provided evidence that the incident records did not help them understand why behaviour occurs. They cited that their own experiences offered them more support, which they shared with each other. Yet again we see a lack of person-centred philosophical approaches being practiced.

Leaders therefore need to respond to this discourse within their governance arrangements as these 'experiences' may not always have a positive impact on the ecology systems. Control, coordination, order and regulation are required to govern practices and cultures. From a systems theory perspective, the macro system must fundamentally interlink with the micro system and in order to avoid political and economic pressures the control and coordination must be a contextual fit. Figure 8 demonstrates that governance must be embedded in all of the ecology systems and the findings here have continued to develop my thinking and appreciation of this component of the framework.

5.6 Chrono System Situation

Understanding the socio-historical issues, as outlined in Table 17, and how these may influence practitioners and their careers is important in order to take corrective action within the community. Bronfenbrenner argued that these historical issues can seriously affect human behaviour and cause serious discourse, as in Winterbourne View (2011).

Table 17: Situational Analysis - Chrono System

Situational Analysis – Chrono System		
Situation Criteria	**Research Questions**	**Data Sources**
▪ Socio-historical context of practitioner careers ▪ Social care influences and impact on practice	7. To what extent do social care influences impact on the community of practice?	Primary Data: ▪ Focus Groups ▪ Semi structured interviews ▪ Questionnaires ▪ Life history experience – related discourse Secondary Data: ▪ Previous research ▪ Government reports ▪ Website information

5.6.1 Research question 7: to what extent do social care influences impact the community of practice?

According to the symbolic interactionist perspective, the highest levels of social influence involve meaningful communication of verbal and non-verbal symbols or cues. Such high level meaningful communication requires participants within the community to share the meaning of these symbols or cues, however, the findings here account for the opposite in the present situation. The members of this community of practice are socialised to understand and react to different meanings due to a weak leadership, policy and governance structure.

The communities that influence us include not just the groups into which people are born, but also those with whom individuals frequently associate as they make their way through life and their careers. According to the symbolic interactionist perspective, shared meanings allow individuals to share the same reality. Identifying the social influences and the impact this has on practice will assist in shaping the PBS Practice Framework and help to improve the stability of all interlinked ecology systems.

Social influence occurs when a person's emotions, opinions or behaviours are affected by others. This can take many forms and can be seen in conformity, socialisation, peer pressure, obedience, leadership and persuasion. The seminal work of Herbert Kelman (1958) identified three broad varieties of social influence:

1. Compliance – when people appear to agree with others but actually keep their dissenting opinions private.

2. Identification – when people are influenced by someone who is liked and respected.

3. Internalisation – when people accept a belief or behaviour and agree both publicly and privately.

These broad components will offer structure to answer this question.

This study identified compelling findings that the economic situation has had a significant impact on the community of practice. A lack of resources and commissioners reducing care packages was highlighted by all participants. This not only prevents the implementation of sound PBS practice, but also undermines the motivation to take PBS seriously, which directly influences the practices of staff. An example of this is captured from a focus group:

> **Focus Group A:** *We often feel that service users should have more staff. We often have to pull from other support packages to help with a service user who is aggressive. We never have enough staff. Staff often get hurt because of this. We just keep getting told that this is all that commissioners will pay.*

This statement demonstrates how the organisation has been heavily influenced by the current economic environment. Most commissioning authorities have reduced support packages and are driving down hourly rates to create efficiencies. Benefits have been cut, which affects social and leisure opportunities for people with autism. This inevitably results in a lack of daily activity, boredom and frustration, leading to behaviours of concern.

Conversely, this perception from organisational leaders has resulted in an invisible institutional policy and practice. Although commissioners are looking for efficiencies,

there is widespread recognition that they have a statutory duty to provide care and support to people who have a need (Care Act, 2015). The issue here is that leaders are not challenging this perception and evidencing this need in their documentation. We have seen this at the micro and macro level and without changes to the organisation's reporting and monitoring procedures to capture the evidence needed to challenge commissioners, this will continue, adding further pressures. We see an element of 'internalisation' here, whereby leaders have agreed to a set of norms that have been established by the commissioners' influence. Leaders are fearful of demanding extra resources from commissioners in case service users are moved to alternative provision when it is perceived that the service is unable to cope with a person's complex behaviours. Challenged or not would result in the same findings of people becoming frustrated and mentally ill. Totsika, Hastings, Emerson, Lancaster and Berridge (2011) highlight the complexities of autism and the rise in mental health conditions. The reduction in support hours may identify a causal link to increased mental health difficulties in people with autism.

The issue of 'compatibility' was identified as an organisational constraint in all semi-structured interviews and focus groups:

> **Service Manager (Ray):** *I have a very challenging service where all six service users should have their own apartments, but have to endure living with each other. They all have major sensory issues and can be extremely hypersensitive to each other's behaviours. My time is always taken up with this service and there isn't a week goes by without something happening.*

Mansell (2007, 2010) highlighted that compatible environments are what commissioners should be aiming for, but the reality is 'compatible behaviours'. In Ray's statement we see a form of compliance. Kelman (1958) offered further clarity on this. Ray has demonstrated a change in his own behaviour in order to accommodate the demands within the situation; however, his attitude has not changed. This may be the result of social pressures to maintain occupancy rates. It may also be due to peer pressure to comply with the major conforming views of the community. Although this is clearly a key pressure for the organisation and the wider practice community, there was little evidence of problem solving and creativity at either leadership or practitioner levels.

These social influences are directly attributed to leaders and practitioner values, as well as attitudes and how behaviours of concern can cloud judgments and perceptions of the context. In the research undertaken by Carr (2007), the central component of PBS was in adapting positive and supportive environments, however, we see evidence here of being influenced more by regulation and practitioners' perception of needs without resolving the problem context, i.e. the environment. Clearly, this can have a significant impact on practice due to these perceptions being inaccurate to the

untrained eye and equally causing quality of life impairments for people with autism. Table 18 offers more clarity at a practice level:

Table 18: Focus Group Questionnaire Outcomes for Capable Environments

Question	*Strongly disagree* *(1)*	*Disagree* *(2)*	*Neutral* *(3)*	*Agree* *(4)*	*Strongly agree* *(5)*
I am capable of implementing proactive PBS strategies to reduce behaviours of concern from escalating.		27.08%	35.42%	37.5%	
I am able to safely support a service user and those around them when they present with behaviours of concern.	35.42%	56.25%		8.33%	
I know how to create an autism specific environment for the service users I support.		16.67%	50%	22.91%	10.42%

The evidence in Table 18 highlights a real discrepancy of understanding in the practice of capable environments. Practitioners indicate that 62.5% are not capable of implementing proactive PBS strategies to reduce behaviours. This will certainly be the impact of not being involved in assessments and the design of the PBS plans at the micro level. Only 33% of practitioners considered themselves competent in creating autism specific environments, as opposed to 66.67% who didn't. Therefore, a lack of knowledge can influence practice negatively and thus result in poor standards of practice.

Mansell and the West Australian Sector Health Check (2007) respectively highlighted that there was a limited capacity of PBS practitioners in the UK and international community. The impact of this is higher cost of provision (Knapp, Martin, Renee and Beecham, 2007), people being placed far from their local communities and increased restrictive practices.

Media and social media have a significant influence on the social care community. Seven of the eight leaders disclosed this in the early stages of their semi-structured interviews, citing "*Winterbourne has damaged the reputation of social care*". In the early research on social media, McLuhan (1995) considered the systems level. He argued that the media itself, rather the actual content of the media, will transform people (micro) and society (macro and chrono). The frequency and interactivity of the communication is what changes people/society's behaviour forever.

Finally, I intend to focus on the socio-historical context. The manner in which humans perceive themselves has a history as long as we have been self-aware or have been able to experience a reflexive consciousness. The perception that an individual has of themself as 'a person' has come to be one of the most cherished conceptions that any individual holds (Carrithers, Collins and Lukes, 1985). The conceptualisation of individual identity has varied over time and is affected by numerous factors, such as the prevailing culture or the "social institutional constraints and their associated normative expectations", within which individual's exist/have existed (Kashima and Foddy, 2002). A combination of social and historical factors contribute and influence the community, as we see in the following statement:

> **Focus Groups A, B, C and D:** *Staff do become de-motivated and undervalued because the pressure is more but the pay isn't.*

All focus groups considered this as a social influence within the community of practice. I apply this statement to Hertzberg's Motivation Theory (1959) and discourse analysis. The language that practitioners use is particularly enlightening, i.e. 'undervalued'. Hertzberg's Theory acknowledges that motivation and job satisfaction can be achieved through positive recognition, however, as I have documented in the findings, there is a fragmentation between practitioners and managers.

The literature has illuminated the social care recruitment challenges, which bear reference to the statement above. Hertzberg's 'factor 2 hygiene factors' address the status of the role (in this case the status that society places on care staff and not just the role); job security and salary issues have caused major discursive dissatisfaction across the community. Incompatible environments for people with autism have increased behaviours of concern and this working condition has become challenging.

Hertzberg argues that if leaders want to increase satisfaction on the job, they should become concerned with the nature of work itself. Being visible and promoting practice leadership, as the literature suggests, would be one of many corrective approaches.

5.7 Conclusions

This chapter was structured by adopting Bronfenbrenner's Ecology Systems Theory and it discussed each of the research questions according to the system levels. I first presented findings of the micro system, which identified a number of practice indicators for consideration in the final PBS Framework. Evidence suggested that practitioners were challenged daily in incident recording and understanding autism and behaviours. Adopting social world/arena mapping helped to shape the practice indicator areas that practitioners require. The initial findings moved my thinking to consider the interrelationships and interconnections with each practice indicator and

the structure of the PBS Framework. Quality of life outcomes are scant at this stage and the evidence suggests there is a strong meso level practice due to no PBS practices in place at this time.

The meso system was then considered, along with how policy impacts on autism and PBS practice, with a focus on how values, attitudes and norms are translated into both policy and practice. We found a disconnection with leaders in the dissemination of policy and a lack of modelling values and attitudes.

I then moved onto the exo system, which extended meso theory. I focused on identifying the practice standards that conceptually fit around the micro practice indicators, whilst also capturing how policy has contributed to the current situation. Practice standards emerged from the findings and started to shape the framework.

The macro level then addressed the interactions and interconnectedness of different policy factors and helped to extract the messy and complex situation. Ordered situational mapping achieved this and captured how information can be lost in translation. Governance was not considered when distribution policy and the rhetoric and reality of the situation were illuminated by leaders. The findings also identified that when the macro environment is weakened and leadership and governance lacks clarity, the direction of vision and intent is lost.

Finally, I discussed the chrono system in the social influences on the community of practice. Adopting Kelam's (1958) theory of broad social influences assisted in illuminating some of the current social influences, whilst the findings also demonstrated that the various ecology systems inter-relate and contribute to the chrono situation.

CHAPTER 6: A HOLISTIC POSITIVE BEHAVIOUR SUPPORT PRACTICE FRAMEWORK FOR AUTISM PRACTITIONERS

6.1 Introduction

This chapter provides an overview of the rationale, design and structure of the PBS holistic framework and in particular it refers to, and responds to, how the framework has been influenced by the literature review. The focus here is specifically on understanding how and why the framework was designed and structured to directly influence good leadership and practice based on the research findings. This chapter will highlight the identified leadership and practice areas that were lacking in the exposés identified in the UK learning disability and autism community and demonstrate how this has been responded to.

The main body of this chapter addresses the evidence-based way in which to lead and practice PBS through the design of practice standards that support and show organisations how to embed good PBS practice in services. Benchmark standards that organisations need to demonstrate for both statutory regulations and commissioning requirements are discussed, along with the outcome and contribution these will make to the community of practice.

A PBS practice pathway illuminates the process of the framework and describes how it is structured and practiced. This chapter will explain how PBS can be applied within a multi-tiered framework, i.e. at an individual (micro) or organisational (macro) level, so that positive systems change can be disseminated and endorsed through transparent governance systems.

6.2 The Holistic Practice Framework Conceptual Model

Traditional approaches to managing challenging behaviour have been largely ineffective in creating lasting and positive change for people living with autism. Positive behaviour support is transforming the way we respond to people with autism and other disabilities when their behaviour prevents them from leading an active life.

Situational analysis has enhanced this study as it has offered analysis from different systems perspectives. As a result it has produced deep analysis, highlighting a full array of elements of the situation, which explicates their interrelations. Mapping and analysing the situation has enabled the empirical construction of the inquiry at a chrono, macro, exo, meso and micro level and helped frame the research into the following PBS Leadership Framework:

Figure 9: Positive Behaviour Support Leadership Framework (Alcorn, 2014)

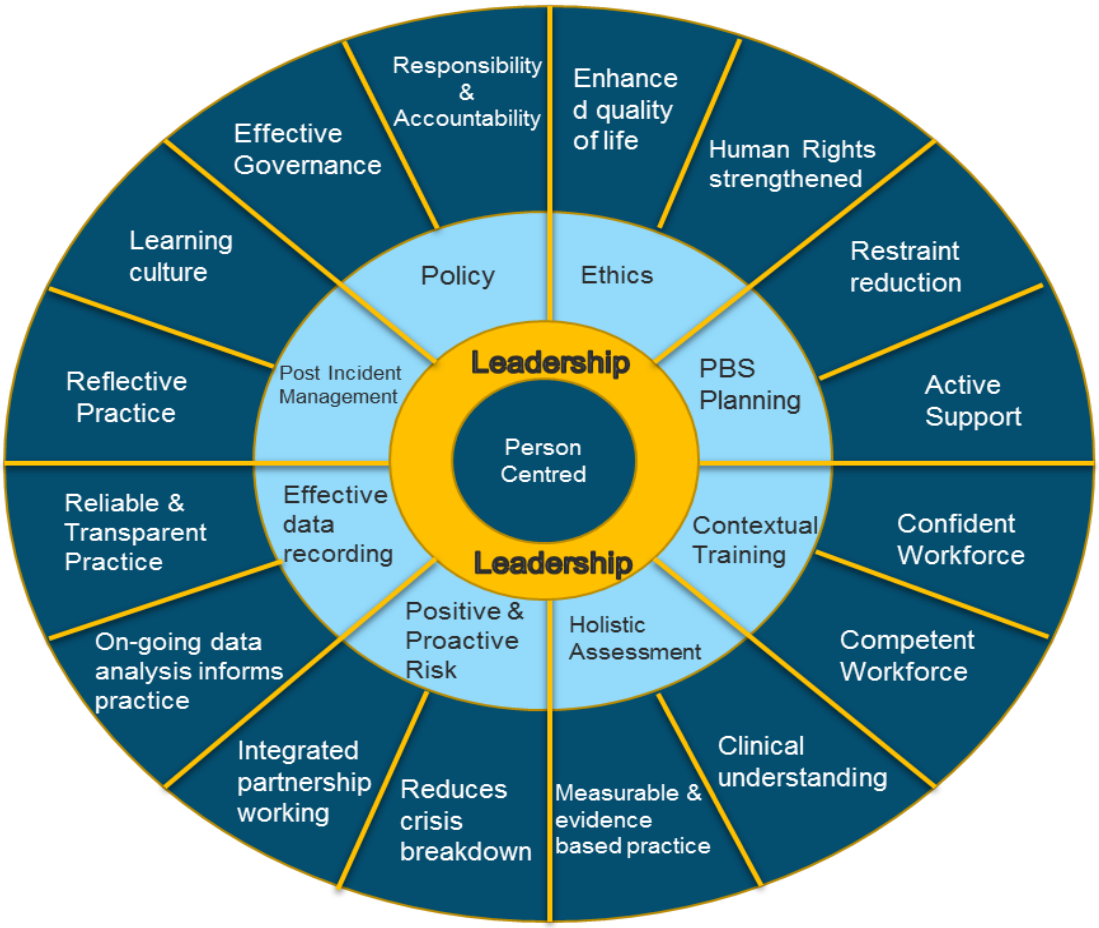
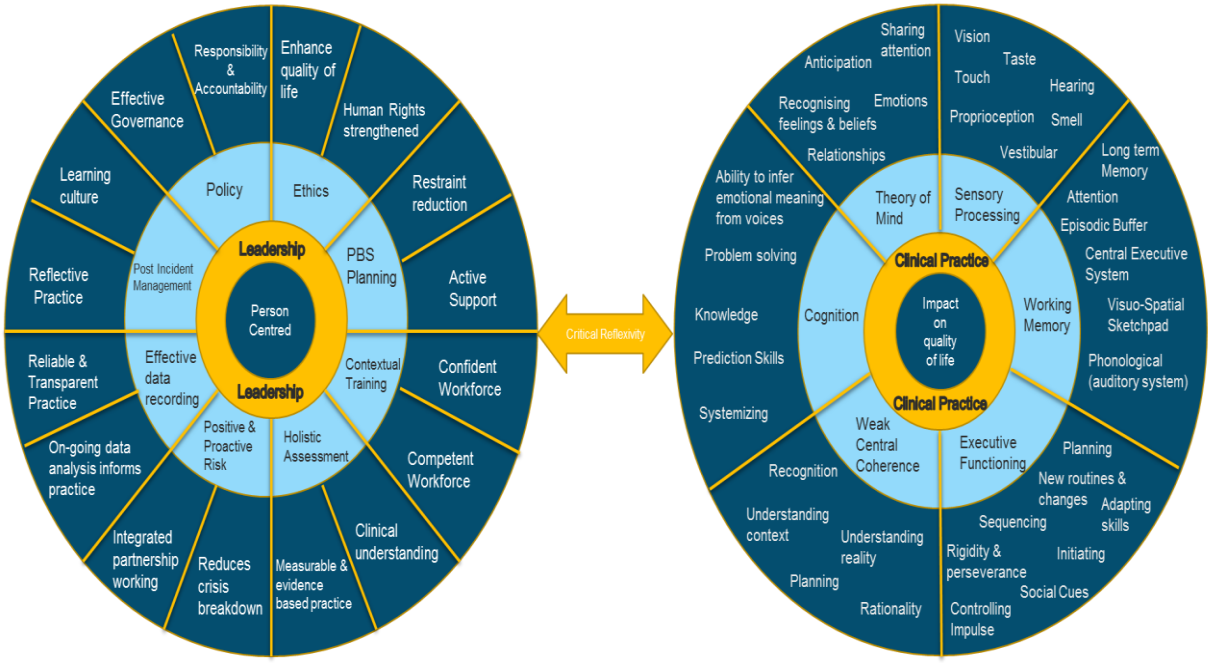


Figure 9 captures the key emergent components that were illuminated from the literature review and findings of the study. Understanding the context of autism for each person is required so that the leadership and practice gap can be reduced. By aligning the components of autism with the theoretical emergent knowledge of the above model, the Holistic Positive Behaviour Support Practice Framework for Autism Practitioners was developed (Figure 10). An epistemological approach was taken in this framework by personally reflecting upon ways in which my own values, beliefs, experiences and political and social identities shape the research. As the researcher, I found it difficult to separate the two components as I came into this research with my own defined values and my interpretation formed part of the model.

Figure 10: Holistic Positive Behaviour Support Practice Framework for Autism Practitioners (Alcorn, 2014)



Critical reflexivity brings together the two arenas and helps to rebalance the current uncertainty in the community of practice and promote learning, decision making and ethical practice. Critical reflexivity offered a number of advantages for this model:

- It helped to respond to the immediate context and in particular offered the ability to process information and create knowledge to guide practice;
- It offered a self-critical approach that questioned practice and how knowledge was generated, and questioned the balance of power from a person-centred viewpoint;
- It assisted in balancing emotions and challenging perceptions.

6.3 Conceptual Model – Person-centred

The requirement for more focus on person-centeredness was a consistent theme throughout the literature. The 'Unified Approach' (Mansell, 2007) commented on person-centred values as being the 'cornerstone' of the 'Valuing People UK' (2001, 2009) strategy and the 'Fulfilling Promises', Welsh Assembly (2001) government report. Person-centred values are not only important in terms of policy and procedure, but are fundamental to achieving outcomes in both interventions and enhancing quality of life. The literature captured a common theme in the undercover investigations with services being led, in the first instance, by staff, with a lack of policy driving person-centred approaches and leaders not governing either philosophy or practice.

The Department of Health's 'Positive and Proactive Care' (2014) identified person-centred approaches as a key element of supporting people. It states:

> Using person-centred, values-based approaches to ensure people are living the best life they possibly can. This involves assisting a person to develop personal relationships, improve their health, be more active in their community and to develop personally. When done properly, person-centred planning processes make sure that those who support people get to know them as individuals.

Rigorous adherence to person-centred approaches is cited and researchers within the community agree this needs further embedding into practice. The social and environmental influences illuminated within the situation capture how leaders, managers and practitioners lose site of the person with autism and focus more on service structures, procedures (e.g. communication strategies such as reporting and recording), the economic situation and numerous other issues. This leads to a lack of personal choice and preferences, reportedly increasing behaviours.

It is therefore essential that a person-centred philosophy and practice is centrally embedded and influences at a systems wide level. Due to the broad conceptual view of person-centred philosophy, this may lead to inconsistent interpretation, therefore this framework adopts the 'Valuing People' (2001) definition discussed in 3.16. Incorporating critical reflexivity into the framework will also help to promote systems change in power relationship thinking, as suggested by Sanderson (2003), and it will re-addresses the balance of establishing meaningful lives and being included in service design and delivery (Wolfensberger, Thomas and Caruso, 1996).

Evidence within the literature has shown that person-centred approaches are fundamentally weak within the broader ecological systems and research is scant in this area (Mansell and Beadle-Brown, 2004a). Without allowing this to restrict the study, an analysis of the numerous discourse situations identified that without dedicated leadership and understanding of leaders, managers and the wider workforce, person-centred approaches is fragile.

In Figure 9, leadership encompasses and supports person-centeredness and influences every level of systems change throughout the situation. It emphasises the need for responsiveness to a person's feelings and needs and has the following defining features:

- Understanding the person first and also how the autism domains impact on their life;
- Understanding and identifying co-existing conditions alongside autism;
- Creating situations where the person is placed at their best advantage and adapting a supportive and functional autism specific environment;

- Acknowledging and trying to interpret what the person is communicating via the behaviour and providing functionally equivalent communication systems to replace the behaviour;
- Analysing the functions of the behaviour;
- Teaching the person skills and strategies for life to increase independence and growth;
- Understanding the emotional regulation of the person within the context of their personal characteristics and autism;
- Identifying the behaviour arousal cycle and developing person specific strategies to de-escalate or design proportionate reactive strategies as a last resort.

Recognising and appreciating how the autism domains (Figure 10), i.e. sensory processing, working memory, theory of mind, cognition, executive functioning and central coherence, impact the individual is important when promoting a reduction in restrictive practices and increasing quality of life.

6.4 Portfolio Practice Standard 1

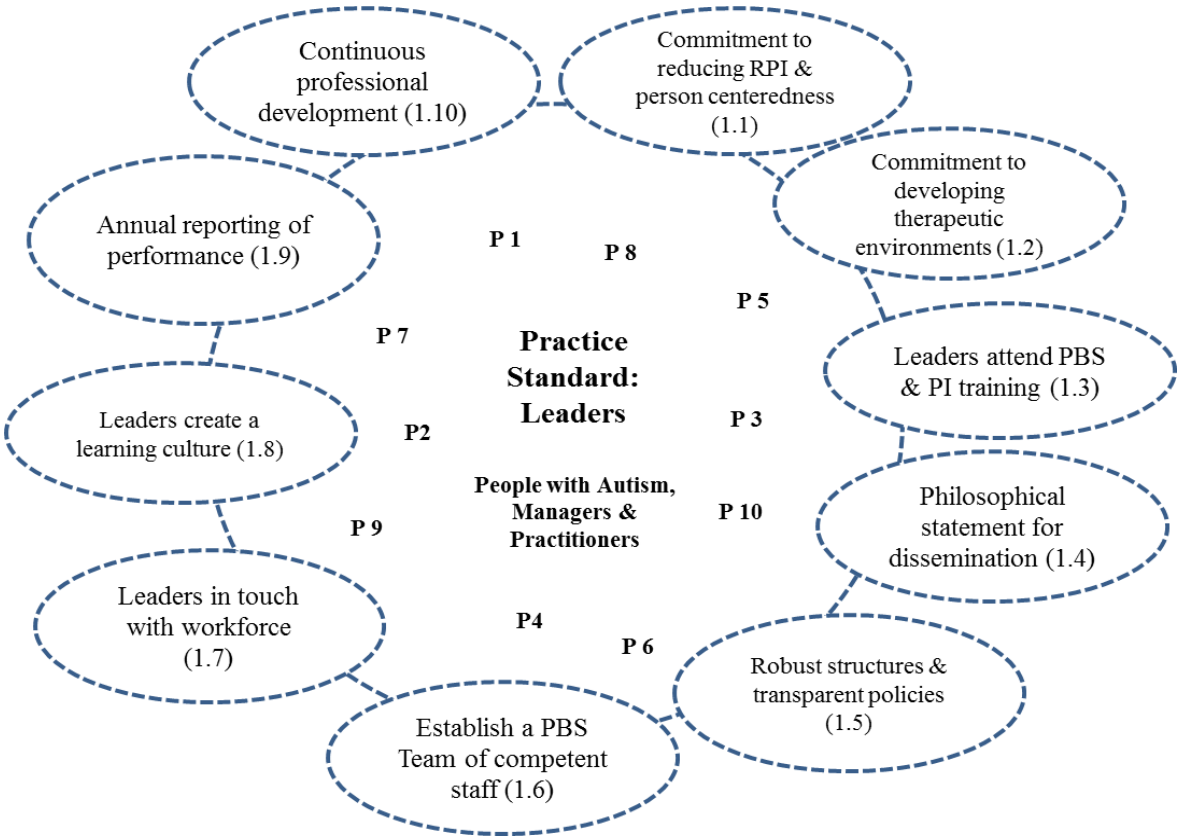
TITLE: Leaders demonstrate a commitment to PBS and have an effective governance framework founded on transparency and accountability for quality and safe practice.

The first practice standard of the framework focuses on leaders' commitment to identifying and minimising the use of restrictive practices and promoting person-centred working within a PBS philosophy framework. This addresses the need for greater transparency and accountability of leaders for quality and safe practices within the organisation (Figure 11).

Limitations were demonstrated in competence, knowledge and process by leaders (Mansell, 1994, 2007, 2010). Numerous government reports outlined in the literature highlighted that effective leadership is required, however, none that were reviewed in this study identified the components of effective leadership in PBS. By analysing the data, understanding the multiplicity in discourse and triangulating with the literature, this practice standard emerged.

From the outset, this practice standard promotes a commitment to restrictive physical intervention reduction and person-centeredness, ensuring this is enshrined by leaders in their policies and procedures.

Figure 11: Practice Standard – Leaders



Responding to creating capable environments for people with autism and leaders' recognition in their organisations of robust person-centred assessments is a core component of this standard and it will go some way to maintaining people in their homes longer. To protect this core component, leaders are required to attend all relevant PBS training so that their knowledge is consistent with a PBS philosophy and framework. This will bridge some of the gaps between leaders and practitioners and help promote more informed decision making and improve the language discourse that we see in the findings.

Under this framework, leaders are required to produce a clear statement of intent (Huckshorn, 2005) for the workforce that outlines their mission on restrictive practice reduction. This requires a systems theory approach in management and leadership and helps in leaders' translation of the statement. The framework helps to make sense of the complexities of the various system levels and offers structure to leaders in terms of making permanent changes. It could be argued that leaders can still influence the systems for their own purpose, however, the multi-collaborative approach within this standard and throughout the framework reduces this. Leadership is disseminated and is considered in this standard to influence the remaining standards (system levels). Establishing robust structures and transparent policies via engagement with people promotes effective relationships, continuous discussion and improvement (Senge, 1990). This will require leaders to have skills in relation to the ability to form

relationships and to understand that this is just as important as developing tasks, functions, roles and positions.

In his six core strategies for restraint reduction, Huckshorn (2005) identified that creating 'champions' at various levels of the organisation can promote this mission. Embedded in this standard is a clear process that promotes delegation reduction tasks to PBS champions where practitioners are accountable for reduction actions during day to day routines. These roles highlight the dissemination of leadership across the organisation, which can influence the various system levels and convey a consistent message without distortion.

Developing front line focus group sessions between leaders and the workforce continues to influence the mission and creates the "real power and energy to generate relationships" (Wheatley, 2010). Adopting this systematic approach can help shape the environment and will create 'followers'. It unifies the workforce and helps to reduce the weaknesses seen in the rhetoric and reality of policy dissemination in the findings. Where leaders fail to attend PBS training or do not engage with the framework, this can create a discourse that is inconsistent with the principles of PBS, therefore there needs to be a mandatory policy. Senge does offer some warning here that leaders often have genuine vision but little ability to foster systematic understanding and although they may create tremendous enthusiasm, they often only go from crisis to crisis. For this reason, it is even more vital that leaders attend and complete all PBS training.

Training alone will not solve the potential problems for leaders, therefore a whole systems approach is required. Learning from situations, adapting and improving practices need to be promoted within a learning culture. This is a key element of systems thinking and will help leaders to understand the way people interact within the various social arenas. Where leaders do not appreciate or understand how internal and external factors impact on people either directly or indirectly (exo level), systems change will not be supported. Leaders therefore need to engage and align themselves with the internal and external environment for transformation to be most effective (McShane and Von Glinow, 2010).

'Positive and Proactive Care, 2014' identified the importance of leadership accountability and reporting by undertaking an annual audit of behaviour reduction. The literature identified the innovative work undertaken by the Office of the Senior Practitioner (Department of Human Services, 2010) in Australia regarding their monitoring database. Colton (2004) also advocated an analysis of performance. This standard introduces an annual audit of restrictive practice reduction so that emergent knowledge can be generated to influence the remaining ecological systems. These practice standards all support the evolution of the 'psychological contract' and will help shape values, attitudes and norms within the community of practice.

The literature presented elements of tension between leaders, managers and practitioners. A feeling of being undermined at management level, lacking in knowledge to challenge ideologies and assumptions all presented a lack of motivation. Practitioners felt they had no voice and were unsupported by management. If these issues are not addressed, this will cause fragility in the framework. Introducing PBS signals a fundamental change to policy and practice, therefore leaders need to consider change management processes and theoretical approaches in leading change that is currently lacking in skill and knowledge within the sector. This study would therefore recommend leadership and management training as a way of bridging the skill gap.

6.5 Portfolio Practice Standard 2: Policy

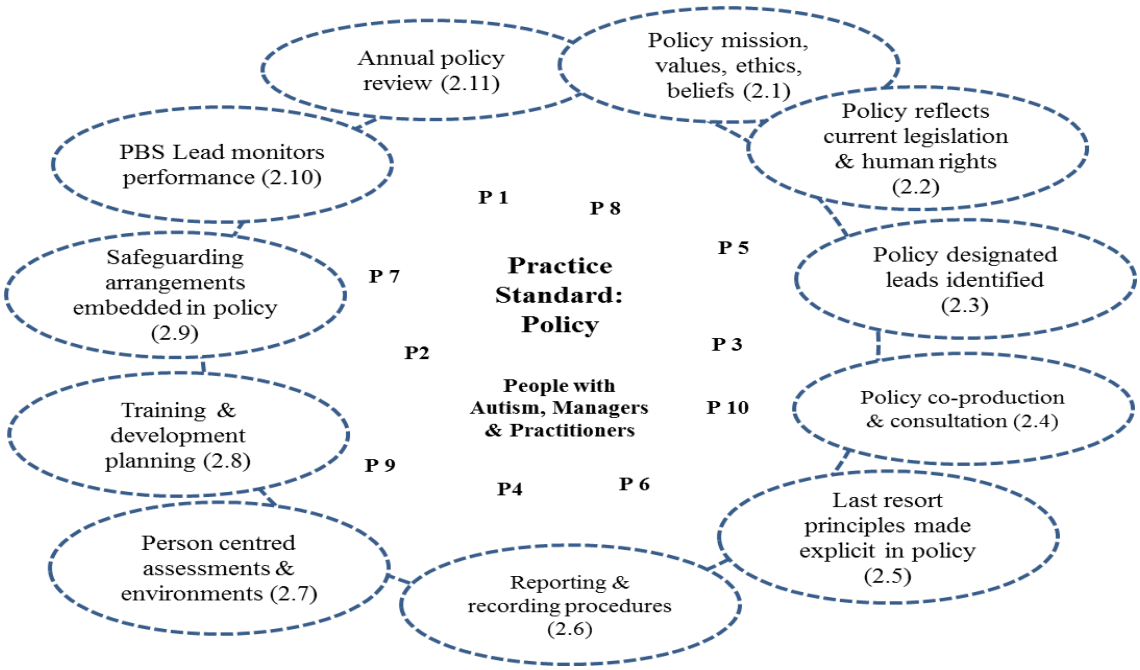
TITLE: Organisational policies are consistent with a PBS framework and promote the principles of reducing restrictive physical intervention and promoting the rights of service users.

This practice standard is aimed at informing policy makers on what legislative and practice standards are required. The literature review demonstrated a wide variety of research and government reports, however, none offer detail on its content. Figure 12 captures this. The literature review highlighted the plethora of national and international policy, however, none contribute anything new or innovative to the field. Although policy has been guided by learning from serious case reviews, we still remain limited in the field with regard to good policy guidance (Mansell, 2007).

Mansell took this further by arguing that by highlighting "challenging behaviour as a separate entity, paradoxically they may have contributed further to a lack of integration of understanding and approach, and an emphasis on symptoms rather than cause". As a result of this, ecological systems have been structured to manage risk and risk containment i.e. more restrictive practices, rather than promoting the 'Valuing People' (2001, 2009) strategy of choice and independence etc. When structures of this kind are created, practice is naturally more restricted.

This practice standard attempts to respond to this problem and to ensure that governance is robust in maintaining the rights of people with autism. This standard aims to consider the wider system and the holistic nature of person-centred philosophy and PBS.

Figure 12: Practice Standard - Policy



Alongside leadership, poor policy design and implementation was a causal factor in the serious case reviews outlined in the literature. Colton (2008) and Allen (2011) identified that policy is a key characteristic of reducing restrictive practice reduction and they considered policy to be a way of capturing positive change in both culture and practice. Currently in UK practice, behaviour policies are often written by senior managers (and even junior managers) who have no background or knowledge of PBS. Therefore the essence of PBS is lost and miscommunicated. The Figure 12 standards offer support to organisations in developing more robust and usable policies.

Leadership remains evident here as the policy addresses its mission, values, ethics and beliefs. The weakness of leadership being introspective remains valid also (Nunno et al., 2011). A policy that does not take account of both the external and internal situation will not drive systems change with best practice. Creating a policy designated lead that works collaboratively with the workforce will ultimately create a more successful policy. This will also help with emergent knowledge translation and shape appropriate practice.

Governance of policy has been a fundamental flaw in the community and acknowledged in government responses to Winterbourne View between 2011 and 2014. This standard embeds governance within a system wide approach at all levels. The initial findings demonstrated the multiplicity of conflicting groups that lead to discontentment in culture and practice, however, when governance is structured and socially organised, coordination, decisions and harmonious relationships can be achieved for the common good. Reporting procedures that are designed to be fit for

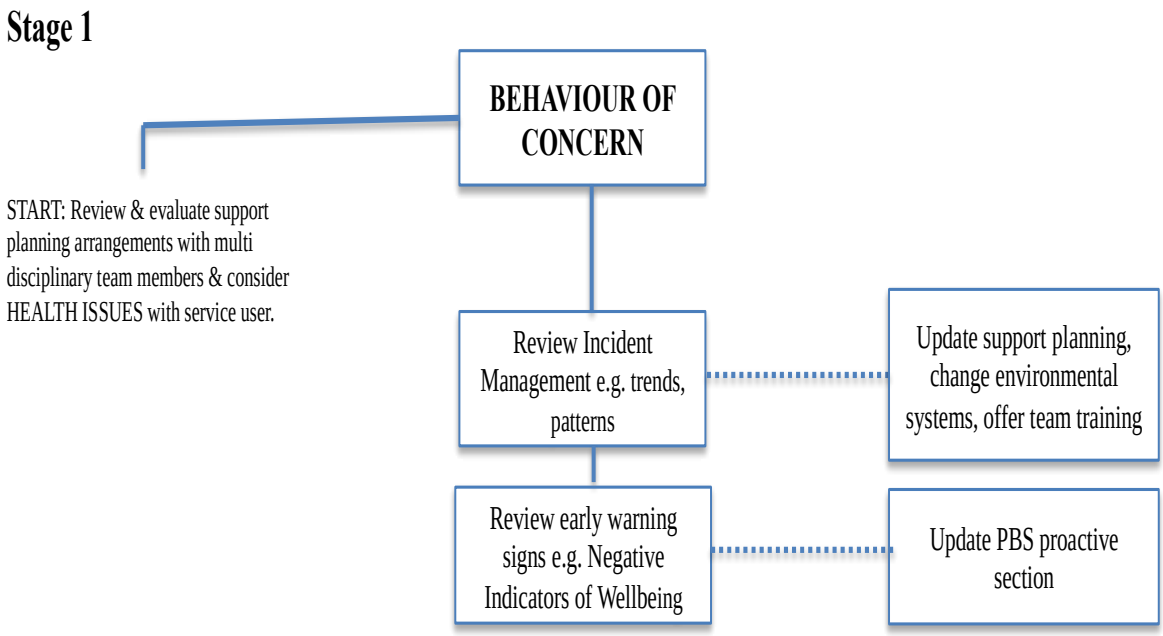
purpose and training that supports the production of knowledge can help inform person-centred assessments.

From a systems theory perspective, there is a danger that practitioners may not acknowledge the fundamental components of the policy and governance arrangements, thereby only viewing this from a macro point of view. Ownership, responsibility and accountability will therefore be affected, which will seriously undermine the policy. Governance structures need to reach every level of the ecological system to be most effective and avoid any loss in translation.

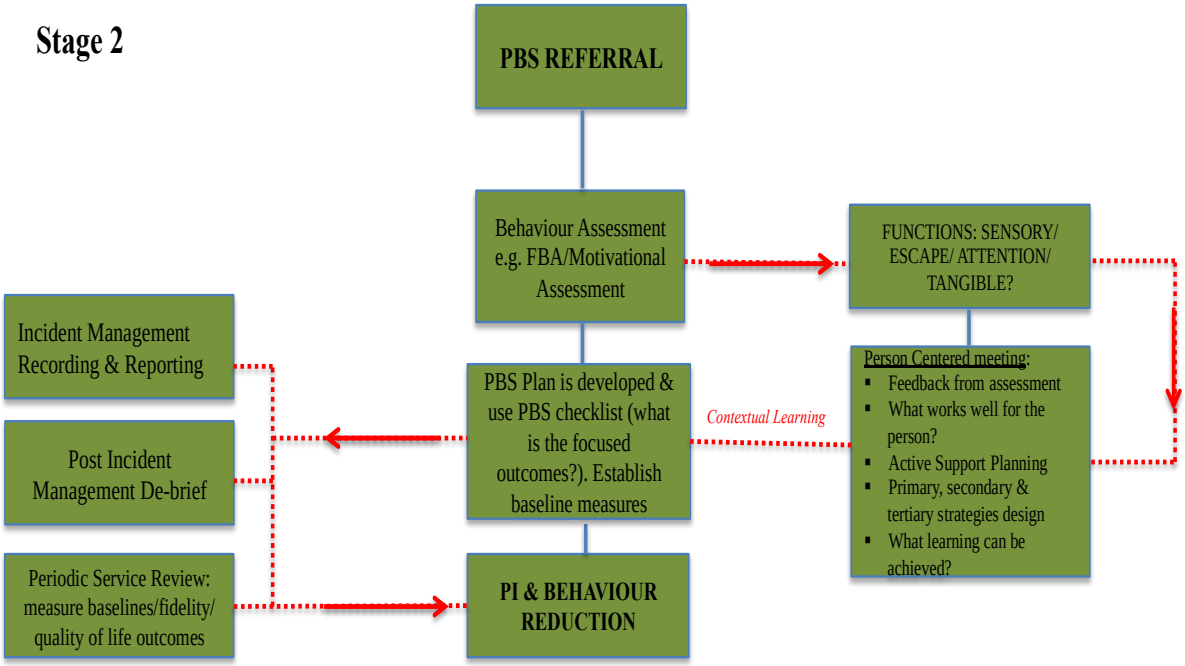
Figure 13 attempts to readdress this problem so that practitioners understand the policy and standards at a systems level. Understanding how they are interconnected and related will help practitioners to conceptualise the framework without losing the micro detail. Leaders and PBS champions must steer this procedure, therefore responsibilities must be incorporated into job descriptions to ensure its success. Currently the essence of PBS in job descriptions is lost and it needs further development within the community.

In order to respond to this, systems theory offers a solution. An open systems approach with feedback loops helps to create structure and order. The PBS holistic pathway offers the community an understanding of the process and the feedback loops promote critical reflexivity and appropriate decision making to ensure person-centeredness is maintained.

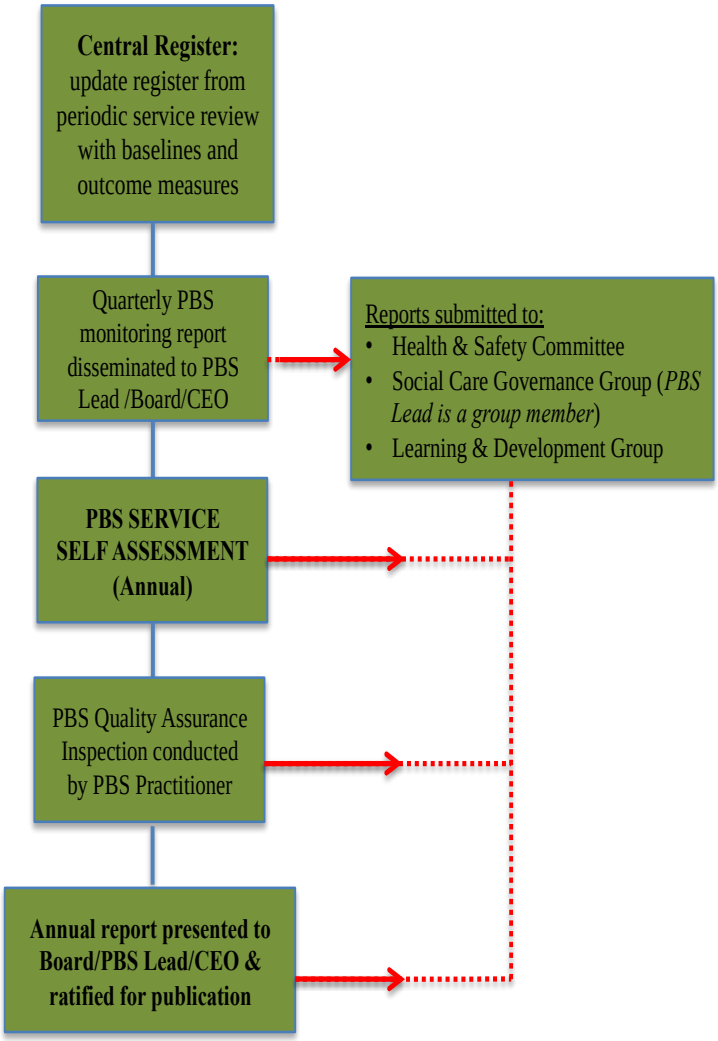
Figure 13: The Positive Behaviour Support Holistic Practice Pathway (Alcorn, 2015)



Stage 2



Stage 3



Stage one of the pathway is at a micro level and promotes collaboration with practitioners to reflect on incidents, wellbeing and the environment. Good facilitation is required by the manager and relies on the manager having a good understanding of the framework. Assumptions regarding a person's behaviour need to be challenged constructively in the interaction between managers and practitioners. The micro level can raise problems in perceived understanding of the situation and cause conflict; however, good facilitation can work through this, particularly where a team is cohesive. Where the team is not cohesive, this is not the case and in fact negative assumptions may even be reinforced.

The second stage takes a broader, holistic analysis and involves the meso and exo systems. Analysing the wider issues helps to establish what (and who) is influencing the systems. Where there are team dynamics at play, these will be illuminated through PBS. The PBS champion will be guided by the framework, applying consistency and working alongside teams to develop understanding. This approach is associated with policy learning, a theory of change. At this level teams are supported to challenge their thoughts and behavioural intentions that result from experience. This helps to develop and achieve the policy statement of intention. This is an important element of achieving the policy mission as the secondary outcomes achieved are concerned with belief systems, values and attitudes. This stage is still susceptible to socio-historical influences from practitioners' past experiences and at times this may dominate stage two. PBS champions therefore need a range of generic and specialist skills to be able to undertake behaviour assessments whilst also facilitating and managing the social and attitudinal dynamics within the team. Currently there is no guidance on this and this could cause fragility in the framework.

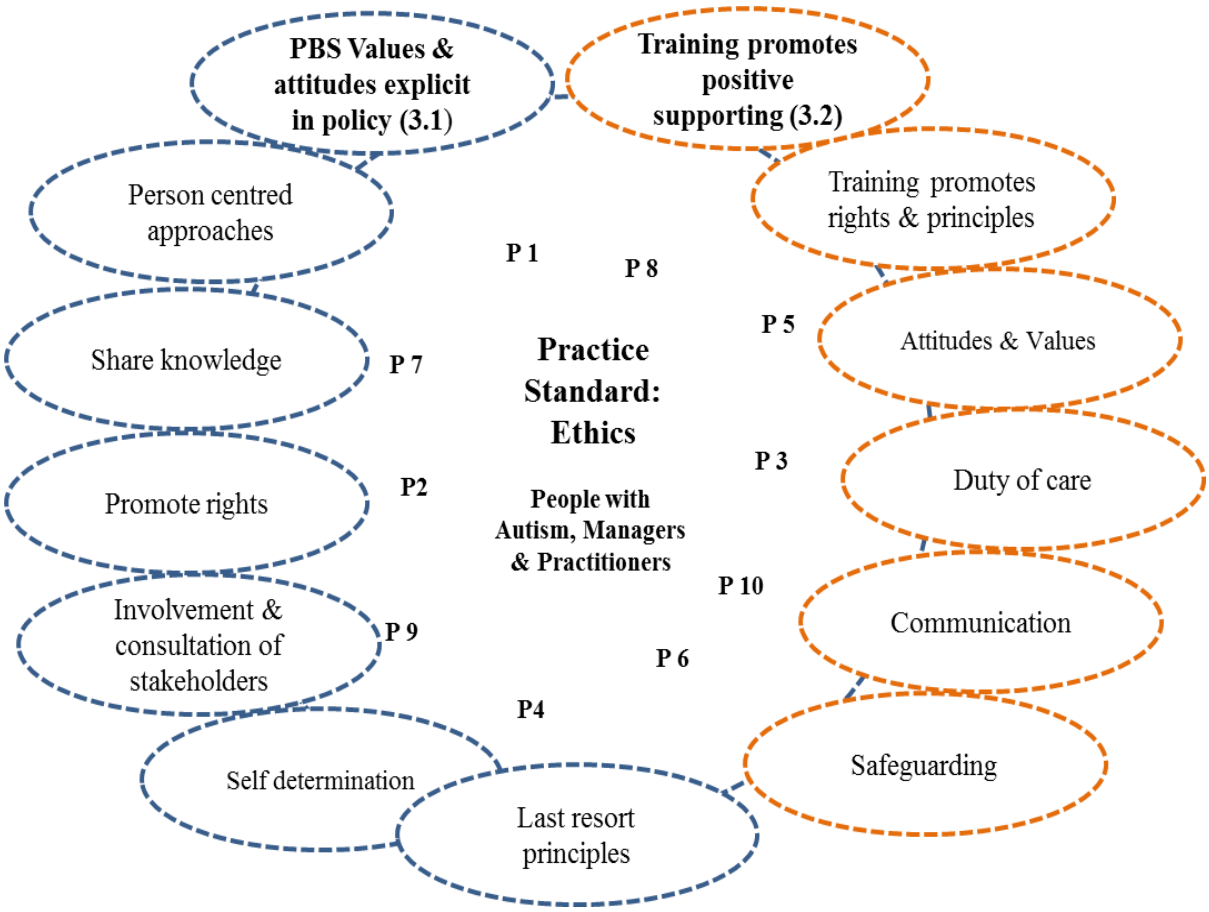
Stage three finalises this practice standard by reviewing the policy and undertaking analysis of performance. The structure helps to govern and adapt the policy. The focus here is on adaptive learning within the eco system and the greater the ability to respond to adaptive challenges, the more successful the overall reduction mission is.

6.6 Portfolio Practice Standard 3: Ethics

TITLE: Promoting the ethical and attitudinal foundations of PBS.

Practice standard 3 ensures that ethical consideration is applied from policy into practice and this is incorporated throughout the entire holistic practice framework. The benchmark indicators that need to be made explicit in policy and practice are captured in Figure 14.

Figure 14: Practice Standard - Ethics



In order to ensure that these ethical principles are embedded into practice, the PBS team will promote them through individualised training and induction processes. The PBS team will particularly focus on duty of care issues and the obligations placed on practitioners to ensure these are practiced and evidenced.

Campbell et al. (2007) stressed the importance of ethical awareness and Seedhouse (2009) suggested that training ethics required more innovative approaches and that the theory-practice gap was still problematic. This standard doesn't just embed ethics in training; having PBS champions working alongside practitioners on a day to day basis will further strengthen this and focus on the benchmark indicators in Figure 14.

Seedhouse (2009) described how ethical myths can be a barrier to ethical reasoning, which remains the case in this standard. Ethical issues cannot solely be leaders' responsibility and must be disseminated across and down the organisation. A danger, however, is that without providing the necessary training to be competent in practice, decisions will be led based on staff assumptions or on regulations rather than on person-centred needs. Training is not the entire solution and, as stated earlier, it

requires a whole system approach. There has been little research in ethics and PBS to date and this topic requires further exploration.

6.7 Portfolio Practice Standard 4: Holistic Assessment

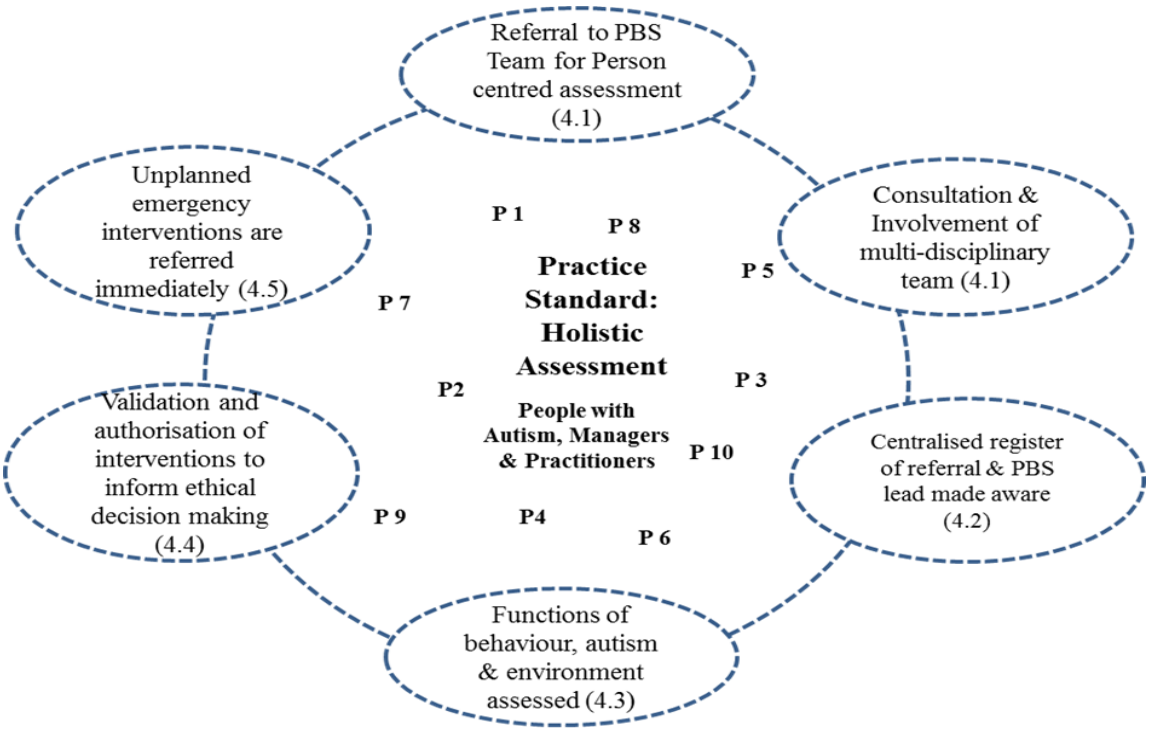
TITLE: An individualised holistic assessment is undertaken and is continually monitored, reviewed and measured through consultation and collaboration by a multi-disciplinary team.

'Positive and Proactive Care' (2014) states that:

> Skilled assessment in order to understand probable reasons why a person presents behaviours of concern; what predicts their occurrence and what factors maintain and sustain them (this area of assessment is often referred to as a functional assessment). This requires consideration of a range of contextual factors including personal constitutional factors, mental and physical health, communication skills and the person's ability to influence the world around them. Patterns of behaviour provide important data, skilled analysis of which enables key areas of unmet need to be understood.

The holistic assessment process is systematic in identifying problem situations and behaviours and assists in understanding the personal context issues and interventions required from both a PBS and autism perspective. Figure 15 captures the benchmark indicators within the standard.

Figure 15: Practice Standard - Holistic Assessment



This standard is unique as it not only addresses the functions of a person's behaviour, but also the autism specific issues that a person faces on a daily basis. The framework offers a selection of autism assessments alongside the functional assessment tools to support clinical understanding. These include:

- Sensory processing assessment;
- Autism needs assessment.

These assessments feed into:

- Environmental assessment e.g. what is toxic to the person?
- Cognitive assessment.

The framework has been purposely designed to be transferrable to other fields of health and social care, therefore these assessments can be changed according to the field in which practitioners practice. This standard directly responds to the Think Autism Rewarding Lives (2014) strategy and will support practitioners in redesigning environments to be supportive and functional and create lasting systems change.

At the core of this standard is the underlying assumption that behaviour is predictable, occasioned by environmental events and it serves a purpose or a function. The effectiveness of PBS assessments has been greeted with varied responses, with some researchers arguing this benefits practice (e.g. Scott et al., 2004), whilst others consider this as an unwarranted overgeneralisation of results (Gresham, 2003). They

argue that the community lacks the technology to intervene effectively with complex behaviour and many practitioners lack the expertise to implement effective functional assessments and support. Holistic assessments can be time consuming and therefore collaboration with staff is vitally important to reduce timescales, but it can equally result in varying assumptions and perceptions that can not only delay the process but also result in subjective bias.

Direct consultation between the PBS champion and practitioners will help to debate context, offer suggestions on intervention strategies and provide detailed specific instructions for implementation through modelling and coaching. This process can improve the fidelity of teaching both theory and practice and add to capability and capacity building of the workforce (Mansell, 2007). This methodology remains consistent with a systems-based approach as it is cultivating local expertise through regular contextualised practice training where practitioners are learning 'on the job' (Crone, Hawken and Bergstrom, 2006).

This scaffold approach allows practitioners to receive ongoing feedback and gain experience of assessments. Although the holistic assessment is aimed primarily at understanding the person's needs, the secondary outcome is that it creates a community of learning through critical reflexivity by using a common framework. The discourse of language and non-human elements such as procedures, reports and records will be more consistently applied and understood with rights and ethical decision making at the centre.

6.8 Portfolio Practice Standard 5: PBS Planning

TITLE: Person-centred PBS plan is developed from assessment information and through the involvement of the service users and those around them.

PBS plans require a high contextual fit and therefore the holistic assessment must advise the plan. Even when a plan has been designed with an emphasis on contextual fit, there is no guarantee that a PBS plan will be implemented as intended (Telzrow and Beebe, 2002). In fact, most of the research in this area indicates that even simple plans are more likely to have inconsistent, rather than strong, fidelity of implementation (e.g. Noell et al., 2005). However, not all plans are doomed to failure. Figure 16 provides an overview of the practice standards required in PBS planning and there are two phases that provide an opportunity to improve plan fidelity, which are adopted within this framework and within the principles of PBS:

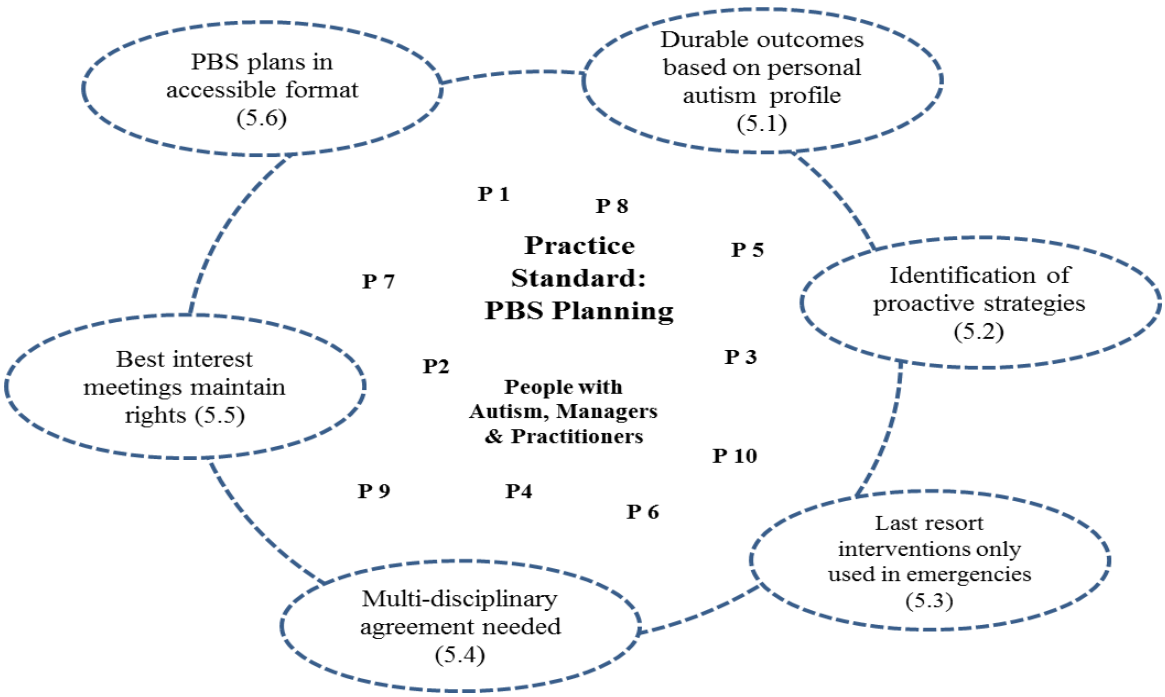
1. During the process of practice standards 4 and 5, steps are taken to ensure that the plans are acceptable to practitioners and other stakeholders and feasible with current resources. Collaboration is key to ensuring success.

2. During the implementation of the plan, practitioners can choose from a number of proven techniques to improve fidelity of implementation. This will support their understanding of why they are doing what they are doing, but also promote confidence in the strategies as these are known to the practitioner.

Within the positive behavioural support framework, the plan includes both proactive strategies for reducing the likelihood of the occurrence of the behaviour, and reactive plans for managing the behaviour when it does occur (Allen et al., 2005). This clearly differentiates between PBS and restrictive physical intervention as a last resort. This will support practitioners to engage with proactive strategies and use a gradient approach in the event that more restrictive interventions are needed.

Currently there is a weakness in PBS planning due to insufficient expertise in developing and implementing the plan. Typical efforts to resolve this focus on bringing external professionals into the organisation, however, this will not resolve the internal problem of capacity and external professionals do not have the resources to offer dedicated time to services.

Figure 16: Practice Standard - PBS Planning



Offering one-off workshops of intensive training is also unlikely to rectify the situation. This would offer limited exposure to a small number of practitioners, but not the experience of regular feedback to build knowledge.

A system-based solution remains consistent and runs through from the holistic assessment into planning. Here, we can see the importance of the PBS champion role becoming crucial to implementation and dissemination. The PBS champion will facilitate the benchmark standards in Figure 16 and, from the assessment, help to draw out the salient areas. Research has shown that practitioners who take an active role in the process can lead to effective PBS planning and better long-term maintenance of effects (Kamps et al., 2006; Lucyshyn et al., 2006; Luiselli, Putnam and Sunderland, 2002).

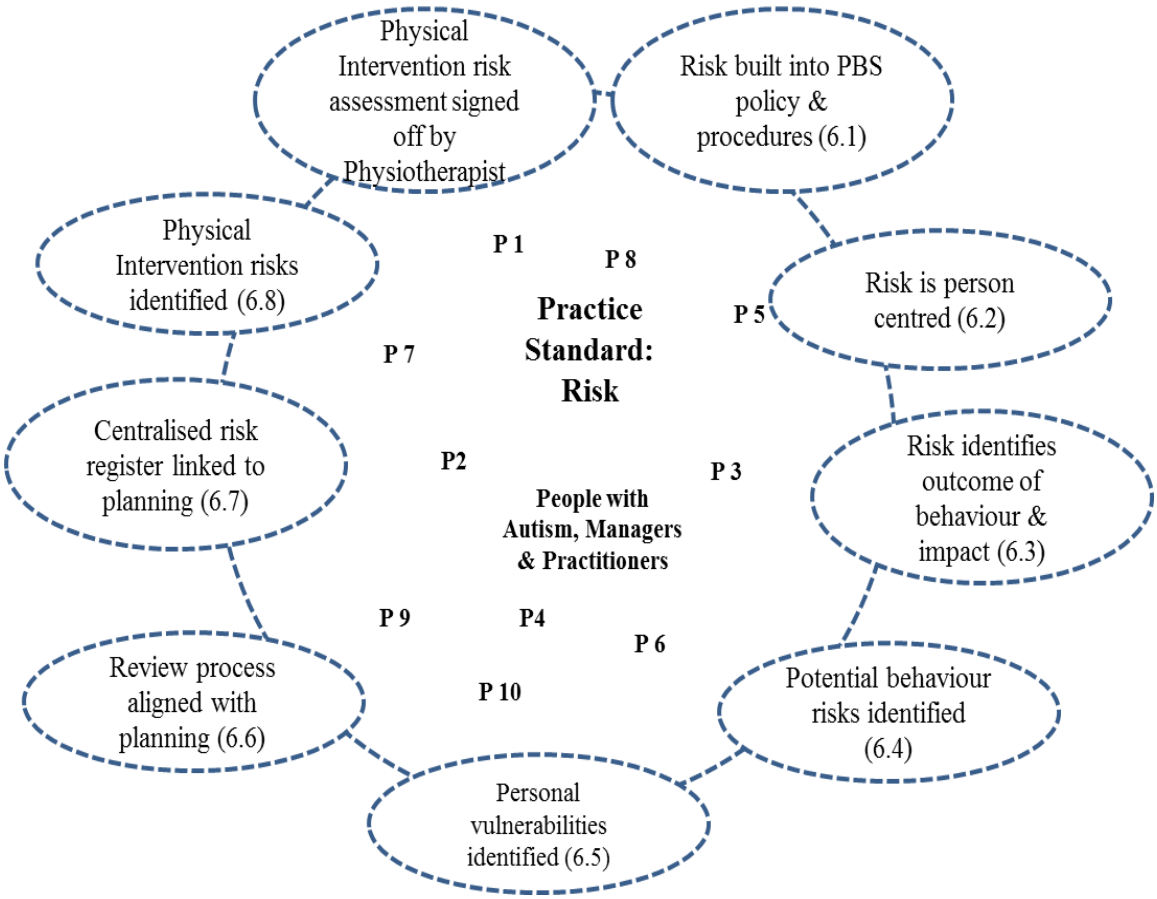
Ethical considerations remain a key aspect of this standard, where best interests are explored to ensure that the least restrictive intervention is used. Offering accessible planning to the person with autism also helps to establish their choices, control and self-determination.

6.9 Portfolio Practice Standard 6: Risk

TITLE: Risk management plans developed and fundamentally embedded into the PBS plan and reviewed, evaluated and measured alongside the plan by MDT. Restrictive physical intervention risk assessments have been completed by the PBS team and will be distributed following bespoke training.

The aim of this standard is not to take a 'risk averse' stance that then severely restricts a person's life further, with the potential consequence of inadvertently increasing their level of risk (Allen, 2009), but rather to promote opportunities, choice and inclusion (Valuing People, 2001). Policy dissemination remains close to this standard, as seen in Figure 17 (6.1).

Figure 17: Practice Standard - Risk



The practice of risk assessments has historically focused more on the management of behaviour, rather than aiming at the person and their holistic quality of life. The appreciation and importance of maintaining a vulnerable person's right to freedom, choice and control were clearly not a primary practice and the 'Valuing People' (2009) strategy lost its way. Human rights were violated and, as Carr (2007) described in his research, social systems of attitudes, practices and structures were more disabling.

The holistic assessment and PBS plan assist in the formulation of a risk management plan and are vital in not only highlighting individual, environmental and systemic issues, but also in portraying the impact on the individual and those around them and a failure to respond appropriately and adequately to their needs. Risk that is fundamentally embedded into planning blends the values and rights of people with autism so that systems change occurs (Horner, 2000).

Research captured a kind of standoff between leaders, managers and practitioners due to the demands at practice level. Staff providing direct support to people with autism state that leaders/managers do not understand the practical constraints they face. Meanwhile, leaders/managers report that staff are simply not able to carry out necessary intervention (Beadle-Brown et al., 2014). A causal effect of this may lower

their expectations but thereby run the risk of PBS plans being ineffective and risk increasing. The solution is systems thinking and ensuring that procedures are based on a learning organisation through regular feedback and consultation.

Mansell (2007) argued that individual risk factors (such as communication difficulties or sensory issues) are widespread among people with autism and environmental risk factors (such as poorly structured environments and poorly trained staff) are also widespread. To promote effective support, these factors need to be considered from a person-centred perspective and formed based on ethical standards and values.

The risk standards are all based on a person-centred understanding, however, research has proven a number of disadvantages to person-centred risk management. Bates and Silberman (2007) argued that life and risk are inseparable and that looking at risk from the point of view of the person rather than solely considering their behaviour is necessary. Risk decision making is also often complicated by the fact that the practitioner or team making the decision does not always comprise individuals affected by the risk and there is a lack of consideration of the person with autism at the centre of the situation. I would argue that risks are inextricably connected with interpersonal relationships. They do not just exist; they are taken and imposed.

This problem is deepened in society as the power of the news media can mean that the actions of staff now have an amplified impact on the reputation of care services and on the social and political context, which results in risk management becoming everything (Power, 2004). This can mean an even more intrusive and obsessive focus on the lives of vulnerable people and it can cause further behaviours and restrictive practices. At a meso level, this results in blame cultures, and at a micro level, a lack of workforce cohesion, all of which becomes more important than the lives of the people being supported.

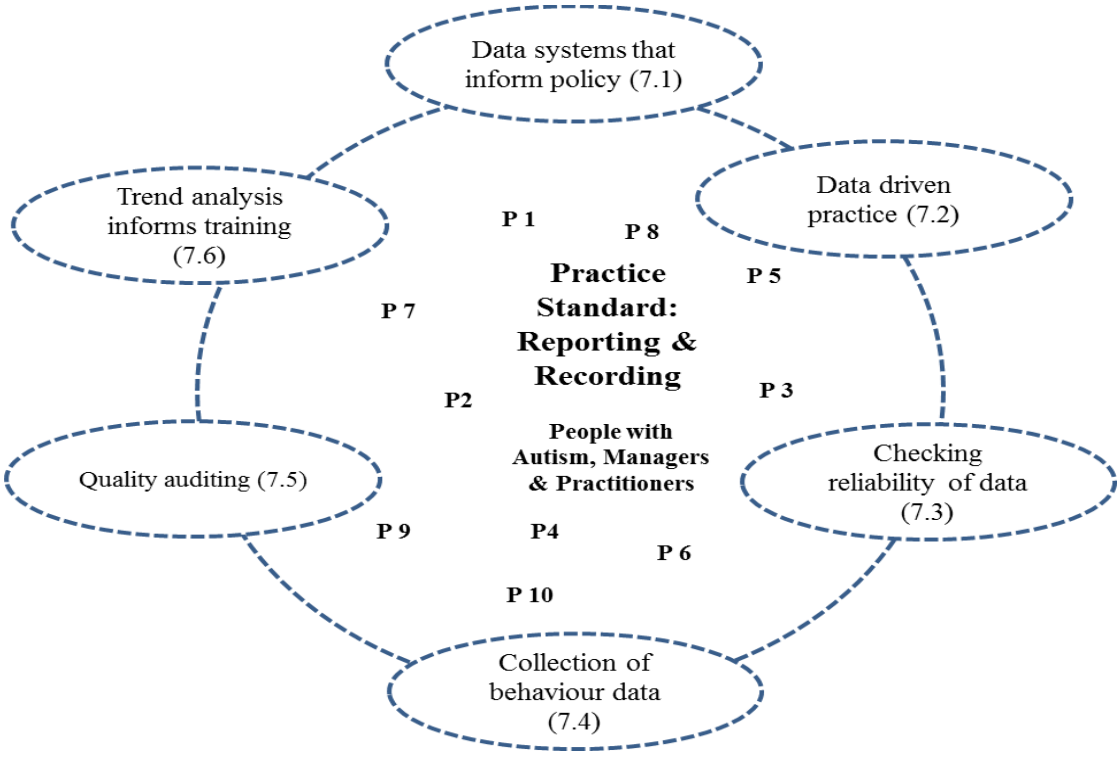
A person-centred approach, with a focus on the person and strategy building supported by policy and practices, can build an alliance of supporters around the person and help cut across entrenchment and generate new and creative ways of providing the service. This requires organisations to prepare and face up to this challenge. Within this framework, taking a multi-tiered approach to risk that holistically considers all contexts will support this journey.

6.10 Portfolio Practice Standard 7: Effective Reporting and Recording

TITLE: Effective data, reporting, recording and reviewing practice is in place to inform practice and organisational priorities which are aimed at reducing restrictive physical interventions.

Effective intervention is based on a comprehensive understanding of the person and environmental circumstances influencing his or her behaviour. Effective data and recording and reporting methods to systematically evaluate behaviour, systems and practices are required to ensure reduction in restriction. Figure 18 captures the benchmark indicators in achieving this standard.

Figure 18: Practice Standard - Reporting and Recording



Assessing fidelity of implementation is as important as assessing effects on behaviour and this is the aim of this standard. Without documentation that the plan is implemented as designed, a lack of beneficial outcomes becomes doubly problematic – it is not possible to assess whether the plan designed by the team has made a difference (Crone and Horner, 2003). Unfortunately, asking implementers if they have implemented the plan is unlikely to produce accurate results (Noell, Duhon, Gatti and Connell, 2002), so other methods of recording and reporting are needed. LaVigna and Willis (2012) argued that models that do not capture measurement and the minimisation of negative outcomes are not truly a PBS model. This practice framework requires the organisation to construct a system that provides baseline data of current practice and then use this data to set goals for improved performance, whether this is for the person with autism or autism practitioners.

Huckshorn (2005) suggested that the fit for purpose data systems play a central role in the organisation's policy and should be considered as an immediate way of ensuring safety; this offers staff the opportunity to discuss and learn while it is fresh in their minds. This also allows for meaningful corrections of the PBS plan and offers a

feedback loop to planning so that data drives practice. The use of witnesses also offers various understandings and interpretations of behaviour (Allen et al., 2009). Studies have shown, however, that the use of standardised terms and jargon in recording can actually restrict learning (Needham and Sands, 2010). In order to ensure the fidelity of information, generalised terms such as 'aggressive behaviour' need rewording to the precise account, e.g. Sally hit James in the face, which will offer more accurate analysis and the development of focused interventions. Training programs must acknowledge this.

Recording data is essential to determine the relevance of PBS interventions and should only occur following detailed consideration of the issue and whether it warrants any intervention. This is a vital component of the recording system as it captures that the rights of the person have been maintained and demonstrates justification on the part of the practitioner. The data helps to analyse the function of the behaviour in an objective way, as well as to identify the most appropriate intervention. The collection of data is required to measure changes in wellbeing and behaviour, whilst also assessing the impact and effectiveness of interventions and whether quality of life and systems change is being promoted and supported.

Reporting and recording requires a systems approach that centrally correlates this information for the purpose of the individual and organisation. The literature has captured the lack of emphasis on recording, reporting and monitoring and the subsequent excessive use of restrictive practices and lack of monitoring (Challenging Behaviour Foundation, 2012; Care Quality Commission, 2012). Organisations in the UK do not offer mandatory training in incident recording or reporting as this is not a statutory requirement. Training also does not focus on values and attitudes in report writing, therefore assumptions and opinions can influence the future analysis of these reports. Although policy identifies that good practice should not be influenced by these factors, the reality proves otherwise. Training offers part of the solution, however, it cannot solely resolve this problem and again a systems approach is required from leadership and policy drivers to ensure consistent procedures that can come together and analyse the various information.

In order to evaluate the effectiveness of the reporting systems, a fidelity check is completed for each service user. This concept was based on the work of LaVigna and Willis (2012) so that quality of life could be reviewed for both the person with autism and their practitioners. A template is provided in this practice framework, which helps practitioners to structure the process and ensure the correct information is gained. The Periodic Service Review, as it is known, also cross-references with any best interest meetings where restrictive practices might be needed, and it triangulates information for analysis. This ensures that more restriction does not creep in and keeps rights firmly at the forefront of practice.

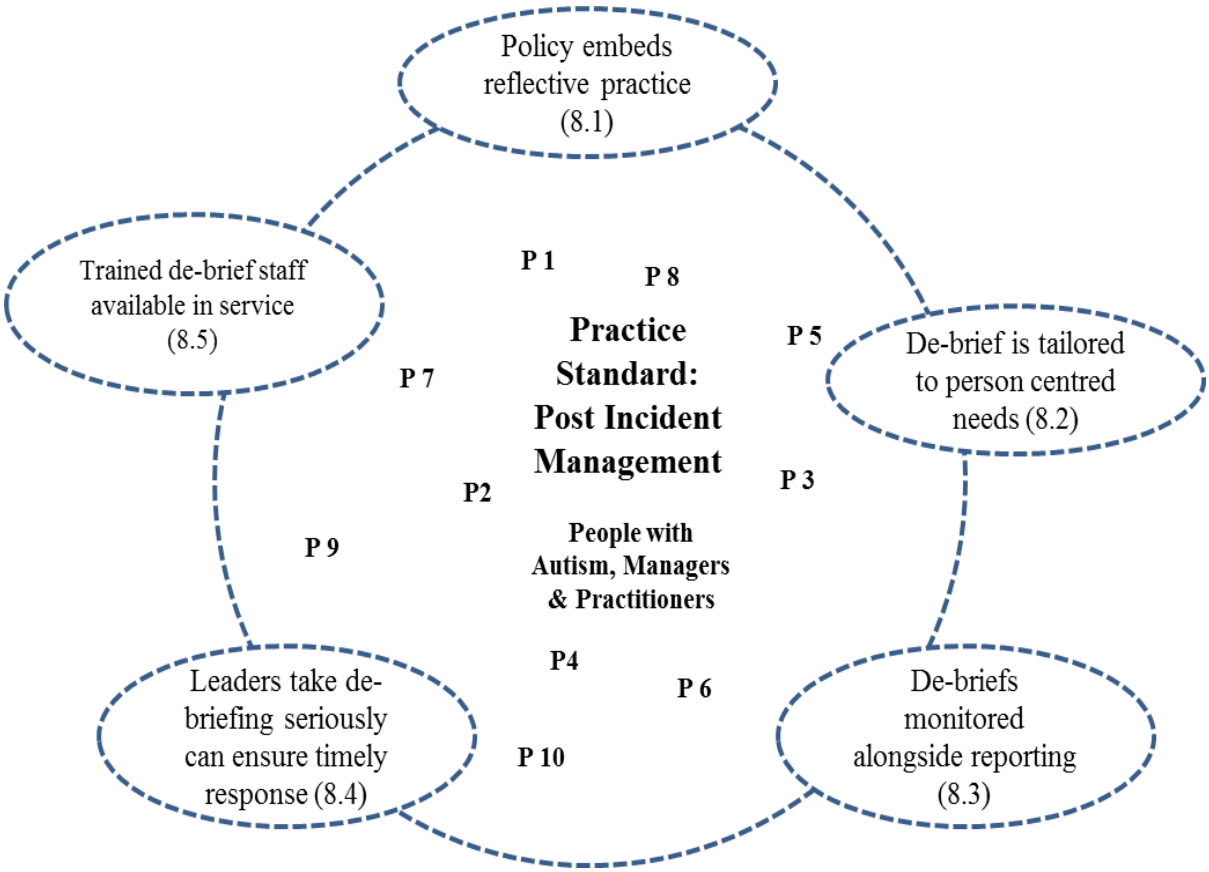
Staff who facilitate such sessions, e.g. PBS champion or manager, will require formal training to hold such a review; however, currently there is no such training available. Facilitators would require the ability to present group facilitation skills, and have the capacity to separate concrete behaviours and contextual factors from the emotion associated with certain incidents. The facilitator would therefore need to be sensitive to those participating in the review and have the ability to manage what at times could be an emotionally charged environment. The literature and findings have demonstrated that managers lack the necessary skills in both PBS and managing behaviour, therefore intensive training would be required before embarking on such an approach and further work within the community is needed to address this.

6.11 Portfolio Practice Standard 8: Post Incident Management

TITLE: Promoting post incident reviews as a learning tool in order to reduce behaviour incidents that are at risk of leading to restrictive physical interventions.

Debriefing is the practice of reviewing an event in order to process parts of the experience, reflect and learn from it. In the context of PBS, debriefing is considered a tertiary prevention strategy and a quality improvement principle. Debriefing is part of Huckshorn's (2005) leadership model. There is increasing research demonstrating the effectiveness of debriefing in reducing restrictive practices, however, to date there is little evidence of the effectiveness of debriefing as a discrete intervention for reducing restraint. It should be noted that debriefing fits within a quality improvement framework, making it difficult to separate from other components of organisational change, such as leadership and training. Debriefing is highlighted as a critical element within many quality improvement studies of restraint reduction, where change at an organisational level is achieved successfully. Figure 19 demonstrates the de-briefing components within this framework and has been cross referenced with the research of Huckshorn (2005), Colton (2008) and Allen (2011) and their de-briefing characteristics.

Figure 19: Practice Standard - Post Incident Management



De-briefing is embedded into the PBS policy and considered an essential component. In a study by Pollard et al. (2007), an examination of policy standards, including debriefing, was evaluated to assess how this improved quality and restraint reduction. The results showed a notable decrease in restraint use. Involving both people with autism and staff equally can help identify systems problems and prevent further occurrences. Despite methodological limitations of studies concerning de-briefing, findings consistently highlight the contribution of successful restraint reduction. De-briefing also supports systems theory and provides a feedback loop for the ongoing improvement of practice, systems and culture. This process can also aid in the psychological and emotional support of individuals and assist in building positive environments and relationships, along with monitoring attitudes and stress/burnout.

Research has highlighted that service user debriefing is not regularly offered and approaches to intervention are inconsistent, with a lack of clarity as to its primary function, what it consists of, when it should be delivered and who should deliver it (Bonner et al., 2002; Needham and Sands, 2010; Ryan and Happell, 2009). Therefore, this needs to be explicitly laid out in the policy. Notwithstanding these issues, there remains a strong justification for the practice. Service users have expressed a desire

for debriefing following restraint, including opportunities to understand and change their responses to distress, anger or frustration. Incorporating this with a team/practitioner perspective can help shape practice and social influences and create learning opportunities and future planning.

Training in debriefing for managers is particularly important and requires the broad organisational overview of senior leadership who are able to separate facts from feelings in a way that ensures all contributors to the review feel safe and supported. There is limited research into the training components of PBS and physical intervention de-briefing, however, evidence in this study suggests that the social, communication and cultural competence of managers is a key consideration for the shared understanding and collaborative problem solving process and this requires further exploration and practice training.

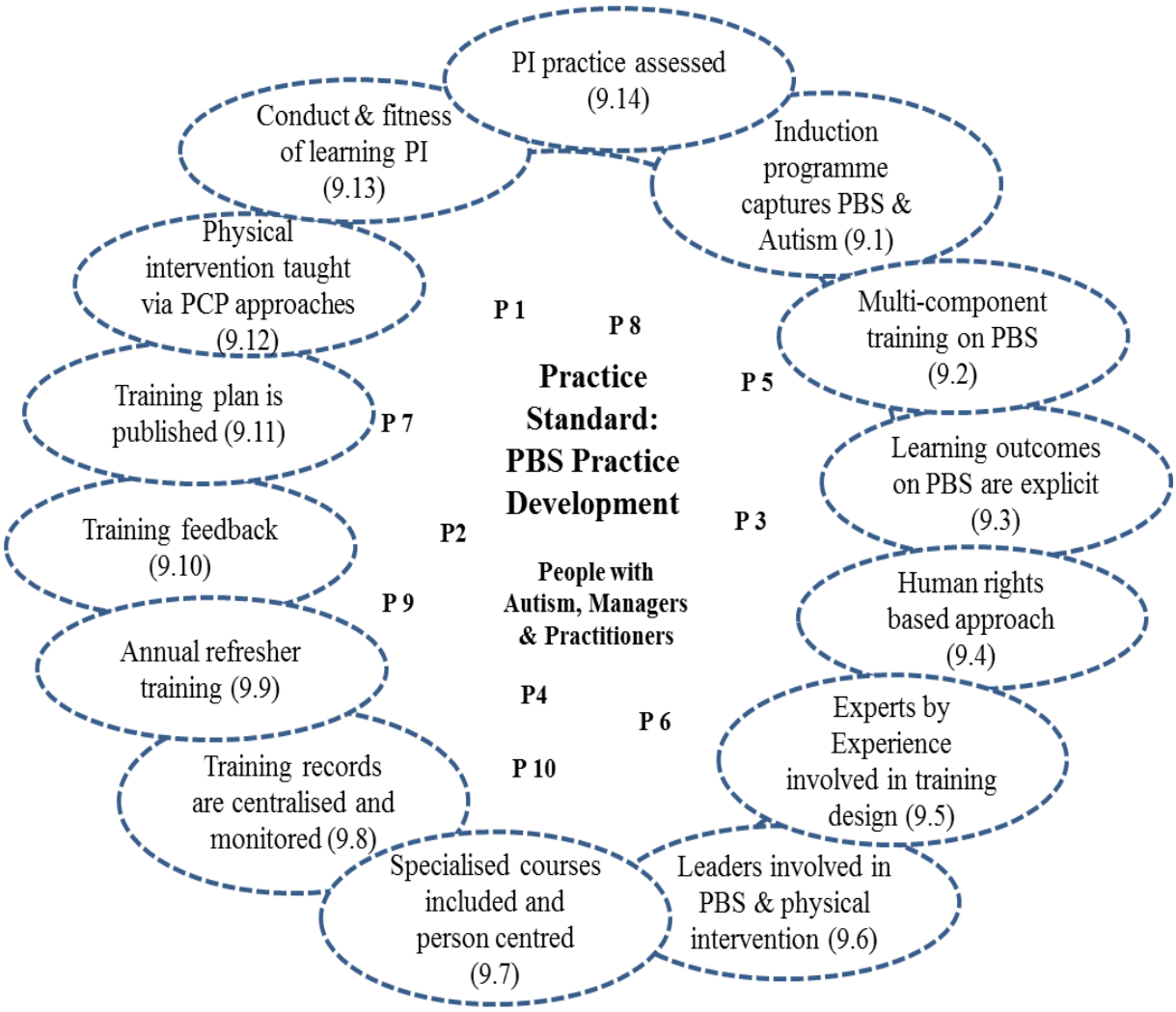
6.12 Portfolio Practice Standard 9: PBS Practice Development

TITLE: An effective PBS practice development-training framework that promotes a broad holistic programme is central to workforce development if safe and good practice is to be promoted.

A lot has been made of training the workforce, including leaders and managers, however, this standard is not suggesting it is the only solution and requires a systems-led approach. What is required, however, is mutual collaboration between external professionals, carers, leaders, managers and practitioners to work together and rather than a knowledge transfer approach, to undertake mutual education involving capacity building that results in total change throughout the ecological system of the organisation.

Emphasis has been placed on more contextualised 'in vivo' training rather than class-based courses. This standard promotes this concept as being ecologically valid and will offer more meaningful training and promote better problem solving techniques and understanding of how the system works together for the common good. Critics of PBS would say that PBS requires substantial expertise in multiple areas, such as systems change, ecological psychology, environmental psychology, ABA etc., as well as the values embedded into various social movements, such as inclusion and normalisation to name but a few (Knoster et al., 2003). A further argument from researchers is that PBS will not incorporate the wealth of evidence-based practice findings into training. However, supporters of PBS argue that this can be taught within a whole systems approach and that PBS has sufficient evidence-based findings on its own merit to incorporate into training. Figure 19 offers an overview of the practice development components required in this framework and how both PBS and autism come together to support people with autism and their practitioners.

Figure 20: Practice Standard - PBS Practice Development



The World Health Organisation (2013) and the Government of South Australia (2013) both commented in their respective research that there is a need to develop and demonstrate consistency between education/training and practice and in order to do this, evidence-based research needs to be incorporated into training programs. Holistic PBS practice development training is central to promoting and supporting change (Totiska et al., 2010), therefore this standard offers a multi component training approach that starts at induction level.

The resources required in delivering PBS can be significant and may result in only training small numbers of teams due to its time intensity and high cost if this were related to Knapp et al. (2007) research on the cost of autism. PBS champions, disseminated across service provision, who can deliver 'in vivo' training and develop and design explicit learning outcomes is one solution to this although these individuals also require intensity and multi component training. Recently the community has seen an increase in PBS courses at both undergraduate and

postgraduate level, therefore organisational investment may offer further validity to the framework.

The aim of this standard is to demonstrate non-aversive practices as despite the effectiveness of PBS, restrictive practices continue to be used (Deveau and McGill, 2009). The promotion of PBS therefore promotes a more proactive culture in practice. Training staff to implement PBS will help people with autism to remain in community settings and minimise the need for expensive out of area placements. In their research, Grey and McClean (2007) reported significant reductions in challenging behaviour and estimated that PBS training may lead to savings of £2,000 per person treated.

Including service user experiences into all training programmes ensures that training is fit for purpose and meets the needs of service users and practitioners alike. Facilitating these real life experiences will require knowledge of the person-centred needs of the case study example, and skill in exploring and debating practice matters. As standards 1 and 2 highlight, leaders must be fully involved in training and communicating face to face with 'experts by experience' to ensure commitment is promoted. Without this being demonstrated, practitioners may consider this tokenistic.

Staff teams should not be looking for quick solutions to what may be lifelong patterns of behaviour. They need to be trained, supported and managed in such a way that they can promote positive interactions that may bring about increased participation, independence, choice and inclusion within local communities. This may require more specialised training to understand the factors that can influence behaviour, such as autism or mental health conditions. This will require a PBS team to have a broad range of skills and knowledge sets within the team, which may not initially be readily available. Organisations may need to implement the PBS Framework alongside commissioning external professionals to deliver elements of this standard until such time as they have developed internal competencies, initially at greater economic cost. However, as Grey and McClean suggest, this will potentially save in the future.

There is a demand on the organisation for annual refresher training and due to the economic situation in social care this will require constant investment in a time where training is often the first to be cut. Training evaluation is incorporated into practice development to continue the promotion of the learning organisation and systems theory.

Competency assessment for practitioners who require training in physical intervention is offered and consistent with the BILD Code of Practice, 2014. A challenge for organisations here is for practitioners to have a certain level of fitness, which is problematic in the current workforce. This will ultimately lead to human resources and health and safety matters where a practitioner is unfit to practice physical intervention. Conversely, they may have good skills in de-escalation. Therefore, this

gives leaders and managers a complex issue to resolve that requires further thinking to satisfy health and safety and PBS requirements.

Consultation and collaboration remains central in this practice standard so that training plans and published material are consistent with the organisation mission. Currently, UK policy does not stipulate how and what information needs to be published and this is left up to interpretation. Adopting a multi collaborative approach with leadership approval would ensure a quality improvement approach.

6.13 Conclusions

This chapter has presented the PBS Framework and in particular considered each practice standard. A critique of the standards in connection with current research offers a broader account and rationale for why certain benchmark indicators have been chosen, whilst it also offers a defence in response to criticism.

The practice standards demonstrate how systems theory has been incorporated into the framework and offers feedback loops to inform leaders and policy and practice direction. The various situations within each standard are outlined and the literature review illuminates how each standard was formed and taken forward to establish the entire framework.

CHAPTER 7: DISCUSSION, RECOMMENDATIONS AND CONCLUSIONS

7.1 Introduction

The purpose of this chapter is to focus on evaluating the results from Chapter 6. The chapter will frame this evaluation within the context of the existing academic and policy literature with the aim of developing new theories. This chapter will evaluate the impact, implications and importance of the findings according to the research questions (Figure 2), whilst explaining how the findings of each systems level has practical relevance to the community of practice. To help the reader navigate through this chapter, references will be made to the appendices and portfolio.

Based on reviewing, analysing and discussing the findings, the chapter will discuss the limitations and challenges this study has been presented with. The final and closing remarks will focus on the emergent recommendations that have been illuminated as a result of the findings and a consideration of where future research rests in order to continue contributing to the community of practice.

7.2 The Purpose of the Study

The purpose of this study was to design, implement and embed a Positive Behaviour Support Framework for Autism Practitioners across a national social care provider. Figure 1 – Focus of Research identified the following components:

1. Core aim: to reduce the use of restrictive practices and to enhance quality of life for both people with autism and support staff.
2. Develop and embed leadership and management practice standards that have been informed by evidence-based research and practice.
3. Contribute to the autism and PBS community of practice.

To achieve the focus of this research, situational analysis was adopted as the single methodological approach and synthesised within the theoretical backdrop of Ecology Systems Theory. Discourse analysis and reflexivity also support the discussion section of this chapter. The data collection methods of semi-structured interviews, focus groups and questionnaires all contributed to assisting with the aims and questions set out in Figure 2.

7.3 Discussion of Results

Figure 2 presents the research aims and questions. Semi-structured interviews with leaders and managers were conducted, alongside questionnaires and focus groups with autism practitioners. All methods evaluated the before and after results of the research and practitioners completed pen pictures of people with autism in order to capture the impact that PBS has on quality of life.

Here, each research question will be discussed, whilst also addressing the impact of implementing the Positive Behaviour Support Practice Framework following on from the research findings. The discussion will synthesise the current literature and where new knowledge is identified it will be critically evaluated.

7.3.1 Research theme: practice standards

Research question 1: what are the key criteria practice standards in developing a PBS framework that will enhance the competencies and capabilities of autism practitioners so that autism practices are predictable and offer stability for people with autism?

There is overwhelming evidence for the efficacy of PBS as an intervention for people with autism who present with behaviours of concern (Carr et al., 1999). In their meta-analytic review, Carr et al. concluded that up to two thirds of published reports on PBS demonstrated positive outcomes, as measured by reductions of restrictive physical intervention. Although there are few published studies, Carr et al. concluded that these interventional effects were maintained again in about two thirds of reports. Although these reports identified PBS as an appropriate alternative to generic challenging behaviour training, none provided a detailed analysis of the core practice content to enhance competencies and capabilities. Thematic analysis was therefore used whilst evaluating the findings set against the literature review backdrop in this work. Chapter 6 identified the practice standards (Figure 7) and the impact of this will be discussed.

The findings prior to PBS implementation capture that practitioners had very little involvement in assessment and PBS planning (Appendix Q: Assessment). However, front line staff have more contact with the person with autism therefore it is appropriate that they are seen as key agents in implementing PBS strategies in a person-centred context. It is therefore vital that training focuses on the competencies and capabilities of practitioners at a micro level.

Skills and competence deficiencies emerged throughout the literature and findings with regards to staff, manager and leader awareness of appropriate interventions that do not restrict people (Mansell, 1994, 2007). Research has also noted the critical need

for specialised training to understand the functions of behaviour rather than focusing solely on physical intervention. Studies have mainly concentrated their efforts on restraint reduction and risk, however, limited efforts have been made in understanding the context of environments and person-centred needs. In addition to this the community of practice has seen further economic constraints, with training focusing on compliance needs rather than person-centred training. Staff recruitment is becoming a moveable feast and lacks stability and policy does not direct the desired learning outcomes of a capable and competent workforce.

This study experienced all of the above challenges. In addition to this, there was a 'silo mentality' (Rankin and Regan, 2004) due to a fragmented understanding of behaviour and as a result the training programme offered to the workforce was equally silo thinking. It was evident in the findings that there was a lack of contextual fit with the policy and training programme, resulting in planning and strategies not being congruent with one another. Silo approaches only encourage singular problem responses rather than a holistic person-centred approach and only result in re-occurring problems and staff burnout.

Competencies and capabilities were also formed from past experiences rather than based on factual, ethical and creative approaches. This formed toxic environments and stigmatised assumptions, which led to restrictive practices. All participants in one way or another apportioned this to the economic state of the practice community and have accepted this belief. Behaviour training was considered to be specialised and only facilitated by a specialist, however, PBS takes a more holistic approach by collaborating with professionals, staff, families and the person with autism themself. Person-centred philosophical connections are at the core and this is considered more favourable and adaptable to the current situation. We now start to see that rather than transfer of strategic information from experts to staff, this comprises a process of mutual education and capacity building within a multi-disciplinary team. Changes to the ecology system are far more successful, as seen in the findings.

The key component of PBS is the need to create durable systems change. As a result, training practitioners, managers and leaders in a mastery of subjects is no longer acceptable. The community needs to understand how to deal with the systems in both person-centred terms and in PBS strategies and contextual fit with the person's autism is necessary. Thus the content of training needs to include autistic spectrum conditions, co-morbid conditions, environment and communication, along with numerous other holistic components (Dunlap, 2006).

A lifespan perspective and durable systems change necessitates greater reliance on PBS holistic assessments. Previous behavioural assessments focused on micro-analytical approaches; although this is retained in PBS, a broader more macro-

analytical approach is required that considers multiple system elements. Although the findings in this study identified that the majority of participants welcomed involvement in assessments, this does bring challenges to the community. Firstly, there is too few competently trained staff to deliver PBS training. There are a small number of specialised courses available in the UK, whilst many practitioners have turned to LaVigna and Willis's work in America. In the UK BILD are attempting to correct this through the introduction of their PBS course, however, achievements are slow. This points to the need to develop higher volume, low cost courses through an 'in vivo' approach to building competencies as practitioners will learn and retain skills in assessments and PBS planning when this is understood from a personal context. Secondly, PBS assessments and PBS planning can be labour intensive, although they are known to be more effective when completely thoroughly. A systems perspective is required here, building in structures and processes that allow for such assessment work. Skilling practitioners in this area is fundamental to the philosophy of PBS as behaviours serve functions and are a window into understanding people's communication.

Thinking has moved on due to the findings and discussion highlighted here and developing competencies and capabilities is now considered insufficient for achieving systems change. Workforce development needs to be much more holistic in its approach to include a comprehensive induction for staff that clearly addresses the PBS vision and policy alongside the theoretical underpinning, in particular noting the experiences of people with autism. Practitioners also require core skills in developing therapeutic relationships, non-confrontational boundary setting, instruction in safe and ethical practices and the importance of monitoring vital signs, and to be empowered to modify planning in real life events. This all needs to be embedded within a reflective practice culture in each of the practice standards addressed in Figure 7.

There was a general recognition that the contextualised framework has had a positive impact on the community in terms of competencies and capabilities (e.g. Appendix P: Codes 87, 89, 96, 100, 105, 107 and 109). There were still a number of areas that required improving and these largely focused on the perceptions of practitioners with regard to the capabilities of leaders and managers. This appeared to be related more to fragmented interpersonal relationships than capabilities, therefore time is required to consolidate the framework.

7.3.2 Research theme: quality of life

Research question 2: what are the quality of life outcomes from implementing a PBS practice framework for people with autism and the autism practitioners?

Quality of life for people with autism can be severely affected when behaviours that challenge or skills deficits are present (Emerson, 2011). Although this can have an

adverse effect on people's lives, what the literature does demonstrate is that behaviour forms a function for the person. It may well present as distressing for those supporting the person, but for the person, it is a method of communicating or coping.

Appendix L (1-4) captures four pen portraits of people with autism ranging in age from 21-58 and including both genders. All share the commonality that their behaviours present as challenging in their services and for the practitioners, managers and leaders. Their erratic and unpredictable behaviours have caused restrictions on their quality of life and are consistent with current literature, e.g. aggression towards others, increases in medication, damaging environments, difficulty accessing the community with confident and capable staff and environments that are not compatible due to behavioural needs.

Although there were some obvious person-centred differences in the findings of the assessment, there were common environmental issues linked to the autism domains. These centred around challenges with executive functioning and being unable to problem solve, predict or structure their immediate environments, and sensory overload of pollutants such as noise or crowds along with challenges in theory of mind and understanding social cues and an appreciation of others' feelings and emotions. All indicated a high prevalence of no control, choice, independence or inclusion in their lives. Moreover, there was a general absence of practice leadership within each of the portraits.

The findings of quality of life here need to be considered in light of the literature context. There is evidence that person-centred philosophy and policy is lacking, with services practicing as 'one size fits all' (Mansell, 2007, 2010). There is a general lack of flexibility in service delivery, with evidence of restriction on choice and control, all of which has a negative shift away from the 'Valuing People Strategy' (2009). Being treated as an individual and enjoying better lives, as the ideological underpinnings of person-centeredness, are lacking in policy and practice leadership being promoted, monitored or practiced in these cases.

As many researchers have highlighted, staff burnout is evident in these pen portraits, which alludes to the demands on competency within the teams, quality concerns and no motivation or platform for management or leadership (Hertzberg, 1959). Huckshorn (2005) highlighted the importance of policy dissemination to increase the psychological contract of teams, however, we see before the implementation of PBS that the feelings of practitioners are out of kilt with creating the right balance of action-centred leadership (Adair, 1973). Thus the focus has shifted from the person to the consequences of behaviour.

Evidence of quality of life outcomes commenced at the start of the PBS Practice Framework when all four individuals received a holistic assessment ranging in functional behaviour assessments, to person-centred autism, communication and

sensory assessments. A multi-disciplinary approach was promoted and this included leaders, managers and practitioners. Following a person-centred planning philosophy allowed the individual choice and control, which provided more meaningful purpose to modify their behaviour. On evaluating the results of this study in the context of quality of life, it was evident that undertaking holistic PBS assessments led to more therapeutic relationships being formed between people with autism and practitioners, who in turn created more effective communication and understanding. The psychological contract improved due to practitioners being involved in discussion, analysis and developing the PBS plan.

There is evidence of goodness of fit (Carr et al., 2007) with the interventions and context of autism. The portraits capture an increase in autism knowledge and understanding of the practicality of strategies in relation to behaviour presentation. What this identifies is that practitioners are responding to the function of behaviour rather than the behaviour itself. There is tangible evidence of quality of life outcomes for people with autism in this study, however, quality of life cannot be considered in a linear sense and what is addressed in these portraits is a multiple dimensional quality of lifestyle change that is subjective to those individuals.

There are a number of common themes between the pen portraits in that all four individuals demonstrated a reduction in behaviours of concern and increase in occupation. It could be argued that there is a danger that staff are not consistent when identifying or describing behaviours, especially when their values and attitudes are effected and when physical intervention training is more prevalent than PBS (Appendix Q). What one person perceives as normal, another may find distressing. With the increase in PBS training, improved record keeping and debriefing, the study identifies greater consistency in quality of life indicators. For example, in Appendix Q language discourse sees a shift when comparisons are made before and after the study, which identifies further quality of life outcomes for both people with autism and practitioners.

Social relationships between leaders, managers and practitioners are evident and identify more visible and confident leaders and managers. There is greater level of happiness within the teams, more self-determination and self-control and more creativity in the delivery of care and support, along with increased inclusion and community involvement. The cumulative impact is therefore evident for people with autism. Although there have been many studies on quality of life for people with special needs, this study demonstrates a unique insight into how the quality of life of practitioners is just as important to consider due to the inextricable link between the two.

In addition to this, and where this study is limited in terms of the longitudinal findings, it does not address the lifespan perspective of maintaining these outcomes

due to the time constraints of the study. It is important to illuminate this area for the integrity of the framework. If leaders do not consider the never-ending systematic process of the PBS Framework, these quality of life outcomes will not be sustainable. Equally, interventions continue and are measured over years, not months. To mitigate this, policy needs to steer and protect quality of life outcomes through the following: ecological validity – for practice to be viable, close assessment and analysis is required within the micro system; stakeholder participation – collaboration is required with professionals, practitioners and family members, who can all contribute to the vision of quality of life; and social validity – consider all interventions in terms of desirability, goodness of fit and their subjective effectiveness with regards to quality of life to ensure values and ethical consideration is promoted (Carr et al., 2007).

7.3.3 Research theme: policy into practice

Research question 3: how does organisational policy impact on autism and PBS practice; in particular how are values, attitudes and norms created when translating policy into practice?

There was a disparity noted between leaders and practitioners' understanding of how PBS policy was disseminated throughout the organisation. Promoting the values, attitudes and norms into practice was not evident prior to the PBS Framework being implemented. There was widespread agreement that the policy offered limited direction and practice leadership, therefore translating this into practice could not be governed successfully. This was due to a large majority of practitioners indicating that there was a widespread lack of support, understanding and trust of policy due to the lack of visibility of leaders and managers. Therefore, the organisational meaning and essence of the message was lost in translation. This endorses previous research (Bullard et al., 2003; Colton, 2004, 2008; Allen, 2011; Mansell, 2007, 2010).

Although following implementation of the PBS Practice Framework the study captures an overwhelmingly high response to being consulted about policy and its vision at leader, manager and practitioner level, the study does capture disappointing results in the second focus group session (Appendix P: Code 79). In this, we see evidence that PBS is still not fully embedded or understood by practitioners. There is a danger here that if the lifespan perspective in policy, as discussed above, is not considered, cultural values may well become toxic again due to no drive and emphasis of policy. We saw this in Winterbourne View where behavioural evidence strongly out-weighed the value base. This element of the findings is significant as ethical decision making could well be affected over time and undo the positive work of this research. Seedhouse (2005) addressed this from an ethical decision stance, stating evidence is visible while values are not visible, transparent or recognisable. In order to mitigate this risk, the framework (Portfolio Practice Standards 1, 2 and 3) has synthesised Seedhouse's (2009) Ethical Grid to promote ethics as the core of the

ecological systems and structures so that ethics govern values, attitudes and norms of practice and conduct.

These results may also indicate that practitioners and the services are still undergoing an element of change and therefore understanding of PBS principles is still evolving and being understood. Dunham and Pierce's (1989) Leadership Process Model will assist in taking charge of this change and help direct both policy and translation so that there is visible monitoring of performance by synthesising this theory with LaVigna and Willis' (2012) periodic service review.

This study focused on how organisational policy impacts autism and PBS practice and centres around values, attitudes and norms. Wider organisational factors such as culture and leadership were identified, which research has paid little attention to (Sturney and Palen McGlynn, 2002), however, in this case these have influenced the implementation of this policy. There are a number of factors that are worthy of consideration, which have all been thematically presented under 'organisational stability':

1. Instability in this research was evident and more prevalent prior to PBS being implemented. All participants demonstrated a similar language discourse, outlining lack of funding to support people with autism and lack of appropriate staffing and accommodation. In the US, Baker and Feil (2000) also identified organisational stability, leadership and staffing structures as a major organisational influence, with similarities evident here.

2. Instability has evolved due to a 'group think' culture (Appendix P: Codes: 20, 38, 43, 44 and 46). This is due to lack of policy vision and direction. Leaders and managers are not promoting the message of policy and therefore practitioners create their own subjective meanings. In this case a lack of available funding therefore means lack of activity and occupation, which researchers have demonstrated causes further behaviours of concern and lacks the spirit of a PBS policy. Lack of motivation has been damaged by lack of vision and intent, with managers having no platform to implement (Hertzberg, 1959). A hidden institutional culture and practice thereby begins to form due to fragmented relationships.

These two instability factors are causing uncertainty in the community of practice. The majority of policy drivers have come from countries such as the US and Australia, however, surprisingly in the UK, up until the Winterbourne View scandal, there was a lack of policy and political interest. The Department of Health 'Positive and Proactive Care' (2014) publication is now central to policy formation, however, this study shows that leaders are still relatively unaware of the publication in terms of

content and understanding (Appendix N: Code 12). Dunham and Pierce (1989) highlight that when policy outcomes are not formed and properly shape the essence of policy this results in the message being inconsistent with the intended values, attitudes and norms in practice. We see evidence of this throughout the systems level.

The impact following implementation of the PBS Framework captures a broader understanding of policy and in particular the national guidance. Leaders demonstrate an improved connection between policy and practice (Appendix O). The dissemination is understood at practitioner level as there is an increased awareness of roles and responsibilities (Appendix P). The organisational functioning has seen an improvement in clinical understanding of practice, which the pen portraits have captured. This study has demonstrated that the practice framework had a direct impact on both the policy and translation of practice. The policy has captured the willingness and enthusiasm of staff to offer resolution focused ideas rather than a focus on organisational instability factors.

The study confirms Mansell's 2010 research suggesting that staff characteristics such as attitudes and values affect provision of services. It does, however, continue to extend this by proposing that the link between staff attributions, the working environment and attitudes to implementing policy also need to be addressed in policy so that the organisational factors identified above are minimised.

7.3.4 Research theme: practice benchmark indicators for statutory compliance

Research question 4: what are the practice benchmark indicators required in order to achieve UK statutory compliance in services and how can these positively influence the exo system?

The findings in this study capture that compliance was the primary aim for the training that was being delivered. Therefore, practice was being heavily influenced in the exo system by regulation. Although there has been a slow increase in policy concerning PBS, national guidance continued to fall short in identifying or explaining what benchmark indicators were required to promote the fidelity of PBS. There was a general acceptance by participants that a set of practice indicators that provide clear standards in fidelity alongside compliance was desperately needed in the community.

Paley (2008) made a valued contribution to achieving this objective in relation to mechanical interventions and called for clearer organisational policy benchmark indicators and more effective internal monitoring with ethical considerations. In her later work, Paley (2012) developed the framework of reduction in restrictive practices by focusing on a PBS approach (Figure 3). Although this offered a valuable contribution to the community, Paley recognised that more detailed practical guidance was yet to be seen, and currently none from a PBS perspective. Research offering elements of good practice were disseminated throughout the community, however,

none synthesised these into a good practice model that was congruent with current UK regulations (Portfolio 1-8). Training of staff in good practice therefore needs to be consistent with the good practice model (Portfolio: Practice Standard 9).

NICHE (2015) guidelines reflected current legislation and person-centred care, which the Care Quality Commission requires services to comply with. Although this publication is widely available, there was a perception by the participants in this study that there needs to be more clinical guidance that more specialist professionals adopt in their practice. None of the participants were aware of its publication at the commencement of this study (Appendix N: Code 11).

The impact of regulation and inspection in PBS terms is currently unstudied so it offers no insight. This is further complicated within the CQC inspection frameworks as it does not correlate with a variety of researches on PBS measures and only its principles (Beadle-Brown et al., 2008). Anecdotal evidence leads to views that individual inspectors vary greatly in their knowledge of and inclination to influence practice in this area. This study recommends that inspectors develop a set of questions to enquire about PBS, particularly concerning policy, leadership, ethics, assessment, planning, recording and monitoring indicators.

The findings in this study captured evidence that leaders, managers and practitioners were unaware of what best practice was and how to achieve this, due to interpretation being required. As a result none of the participants were able to identify gaps in processes or compliance. This study set out to develop the 'what' in terms of practice standards and the 'how' in benchmark indicators. The indicators addressed in each of the practice standards (Portfolio 1-9) have been designed not only according to the community of practice good practice, but also through the theoretical underpinnings of leadership and management theory, governance and person-centred planning theory and ethical frameworks. The process of benchmarking was expanded to analyse not only processes, but also success factors and what the impact of success would look like. This would help reduce the interpretation and lost in translation phenomenon (Meissner et al., 2008).

The impact of benchmark indicators has assisted the community in raising compliance standards and has been noticeable in inspections and CQC reports (Appendix O and Q: Practice Standards). There is further embedding of these indicators still required, however, particularly due to competencies not keeping pace with either practice standards or indicators (Appendix R: Competencies). Consistent de-briefing, regular supervision and reflective practice will continue to improve these areas. It is worthy of note that monitoring of benchmark indicators is required periodically to ensure that all stakeholders who are practicing this framework remain consistent in their approaches. This is to ensure the framework is safeguarded and challenges can be

made to practice where shortfalls are evident. This will ensure the integrity of the principles and overall policy (Mansell, 2007).

7.3.5 Research theme: interactions and interconnectedness of policy factors

Research question 5: how do the interactions and interconnectedness of different policy factors within a PBS context affect practice and what are the dynamics at play that can cause a 'lost in translation phenomena'?

Policy factors concerning cultures have been discussed in the context of values, attitudes and norms, however, they continue to play an important role in interactions and interconnectedness issues. Ordered situational mapping of different policy factors was synthesised with the findings of this study and helped to illuminate the complexity of the situation.

The majority of participants focused predominantly on situations where there has been a lack of leadership, which led to participants managing difficult incidents involving people with autism and their behaviours. Differences in the experience of the participants were hard to interpret given that each member ranged in length of experience in autism services. However, it was noticeable that all participants had been involved in a challenging situation within the three months leading up to the focus groups.

We see in the findings of this study that sub-cultures are developed due to socialisation processes in the organisation. Individuals at different structural levels learn what behaviour is acceptable and how practices should be undertaken. On the basis of this, norms are shared and individuals make assumptions. We have seen this in research question 3, how it affects the meso system and creates an institutional culture and impacts on creativity. The findings capture this at leadership, management and practitioner level, which is illuminated in Table 16.

Leaders are regularly seen re-structuring and re-designing services due to policy demands being connected ever more closely with improving incompatible environments and the message is not being passed down to the workforce, therefore policy and vision is left up to interpretation and is disjointed in practice. The interactions are evident in language discourse within practitioner and leader statements. Considering this from the perspective of Action Centred Leadership Theory and Adair's division of leadership, we start to encounter task, team and individual working against each other with sub-cultures forming that are inconsistent with the vision. We see conflict being created due to managers working against practitioners who are left to interpret behaviours for themselves and who are then criticised for their actions. The result of this is practitioners connecting with one another due to shared experiences and pressures and forming their own interpretation

of the situation (Appendix P: Codes 50, 52, 55, 56, 59, 64), all of which creates toxic interactions.

Managers provided evidence of their frustrations due to having to focus reactively on critical incidents rather than spending time on promoting proactive strategies within an environment. There was a general consensus on lack of de-briefing and reaction tending to be focused on meeting compliance needs rather than people's needs, whether this be the person with autism or staff welfare. This does not allow for systems change to occur and further creates fragmented sub-cultures.

Practitioners were all able to identify a recent difficult experience, which reinforced the areas raised above. Although they were not able to identify the clinical elements of PBS that would help correct this, they all shared the belief that being involved in assessments, discussions and PBS planning would help reduce what had been lost in translation and acknowledged their level of participation as worthwhile to both policy formulation and practice. What has evidently been a lost opportunity is stakeholder involvement and participation to develop the psychological contract.

Knowledge translation synthesised these findings into the PBS Practice Framework in order to accelerate the benefits within practice. Following implementation of the framework, an interactive and iterative process developed and effective exchanges took place between leaders, managers and practitioners, which led to new person-centred knowledge about people with autism. There was an overwhelming response to interactions between all key stakeholders and a perception of a more joined up process through engagement.

There was evidence of interconnectedness not being as robust as systems change suggests following implementation of the framework. This concerned the performance targets of staff to ensure they were focused on outcomes within PBS plans. This was lower than anticipated (Appendix P: Code 97). There were a number of reasons for this:

- Some practitioners' attitudes affected the interactions with policy and procedures and required management intervention;
- Managers not understanding the interconnections between policy and procedures and how refusing to implement certain procedures affected the performance of PBS planning and outcomes for people with autism;
- Leaders unclear in their expectations of practice standards and benchmark indicators, resulting in performance targets not being achieved.

Although governance improved at the local interaction level, there was no evidence of horizontal coordination in forming networks of social arenas of practice. This may require a more longitudinal study of the phenomena.

7.3.6 Research theme: leadership and governance

Research question 6: what are the leadership and governance practices required to promote open and transparent cultures and that can help to positively shape the economic and political environment?

We have seen evidence in the literature and in the findings of this study that leadership is lacking when concerned with communicating consistent messages regarding values, expectations and effective performance management. The development of person-centred approaches in PBS requires the use of a range of tools and approaches. Communicating this message also requires strategies and the task facing leaders and frontline managers is to turn the theory of these approaches into practice that results in high quality person-centred PBS support.

The findings in the above research questions demonstrate that practice leadership was not adopted and there was no shared understanding about what is to be achieved, therefore leading and developing individual staff's knowledge and skills was not a key focus (Mansell, 1994, 2007). This was evident in Appendix P when analysing and theming the results:

- Staff did not know or understand what was expected of them;
- Staff did not have the proactive skills or knowledge in autism or behaviour to deliver on these expectations;
- Support was fragmented to help develop the capacity to meet these expectations;
- Staff were only offered feedback when there was a problem;
- Staff did not have the opportunity to discuss and contribute to individual and team aims and objectives.

There was a general lack of leadership concerning resource management, such as organising, planning and performance management (developing staff's knowledge and skills). The Unified Approach, 2007 highlighted that strategies need to be tailored to individuals and resources are required to support these strategies. These resources focused on environments and personal preferences. The same report, however, highlighted the challenge within the community in that there was a lack of capable environments for people with autism. This was in relation to the physical environment, as well as the economic situation and competencies of practitioners.

So what are the possible factors at play? Why don't leaders lead and managers manage? Increasingly, managers are aware of their responsibilities, but they have to do this against a background of many other constraints on their time and resources, whether this is generated by the needs of people with autism or in response to administrative requirements of compliance and regulation.

Leadership and management responsibilities have grown considerably due to the litigious community we now live in. Managers are required to produce evidence of their working practices in a range of areas, e.g. finance, health and safety, supervisions and appraisals, and they are increasingly being required to deliver against local authority contracts. As a result, leaders and managers' roles become strained and cause ambiguity and conflict, both internally and externally. Practitioners then see less and less of senior staff and assumptions are made based on lack of visibility. Due to this leaders and managers often turn away from practice leadership and focus on administrative tasks, seeking activity that is discrete and achievable, which then becomes the routine. The result of this is evident in Appendix P:

- Code 17: No breaks and working long hours for staff;
- Code 20: Staff become disheartened;
- Code 26: Lose objectivity;
- Code 59: Often left wondering why behaviour happened;
- Code 63: The team doesn't get to discuss incidents. No time to reflect.

These examples can all be themed under a lack of governance and are examples of negatively shaping the environment. The outcome can lead to situations where staff are expected to comply with requests and instructions from the leader or manager solely because of their position.

A systems theory approach to leadership was taken during the implementation stage of this study. Leadership was considered to be a relationship between leaders and practitioners (Kouzes and Posner, 2012). The interpersonal connections created were based on mutual needs and interests. In the main part, the collection of interrelated processes functioned as a whole. The issue of performance target setting and outcomes being affected, discussed above, did result in some disjointed practice. However, considering leadership as a system, the evidence captured increased team working and work orientated towards a common goal of restrictive practice reduction and enhanced quality of life. This approach has demonstrated that it equally works well in conditions of high complexity and uncertainty (Coffey, 2010).

The PBS Framework implemented training for leaders and managers. The aim of this training was to develop transformational leaderships due to the significant alignment with the external environment (McShane and von Glinow, 2010). This approach is congruent with the methodological approach of situational analysis (2005), with this being synthesised within the training. The impact of this can be seen in the leaders' semi-structured interview responses (Appendix N). There is a greater level of focus on governance (Code 84) and a broader understanding of policy and practice in autism services (Code 80). The outcome of this has led to ethical decision making based on person-centred understanding and need.

Despite an increase in leadership and governance, the findings of this study still identified toxic environments, albeit they were reducing due to closer monitoring and role modelling of good practice. There is a danger here that conflict within the systems could develop due to increased awareness and understanding. There was evidence of some underlying frustrations that changes were not happening as quickly as people would like, therefore this requires careful consideration and explicit understanding of how this will be managed and communicated to the workforce. This problem could easily escalate into a significant problem if not addressed quickly and this could lead to two further consequences:

1. PBS planning can be a time consuming process and could easily become overwhelmed by crisis situations and short term reactive strategies being required. These crisis situations once established and not responded to effectively can result in service costs increasing (Knapp et al., 2007).

2. The quality of the PBS interrelated processes see staff cutting corners to respond quickly, however, the consequences of this can lead to strategies being inconsistent with need and the consequences for the person with autism result in their rights, choices and independence becoming restricted again (Emerson et al., 2004).

7.3.7 Research theme: social influences

Research question 8: to what extent do social care influences impact on the community of practice?

The transitions and shifts in a practitioner's lifetime involve many socio-historical events that over time may influence their careers. Understanding these influences will help strengthen and secure the lifespan perspective of the PBS Practice Framework.

Before discussing the findings of the study, it is worth illuminating the theory of social influence in order to have a deeper understanding of the meaning. Social influence is defined as a change in an individual's thoughts, feelings, attitudes or behaviours that results in interaction with another individual or group. The findings discuss the work of Kelman (1958), however, the difference with regard to social influence from Kelman's research is that it makes real changes to individuals' feelings and behaviours as a result of interaction with others who are perceived to be similar, desirable or expert. People adjust their beliefs with respect to others to whom they feel affiliation in accordance with psychological principles such as balance.

We also see that there were compelling findings that the economic situation has had a significant impact on the community and, due to this influence, leaders and managers are not challenging commissioners for additional resources in fear of losing service

users. The influence here becomes one of commerciality and occupancy and appears powerful over a more person-centred value base.

Individuals are seen here as being influenced by the majority: when a large portion of an individual's referent social group holds a particular attitude, it is likely that the individual will adopt it as well. Leaders are not leading in this case, which actually could change managers and practitioners' opinions under the influence of another who is perceived to be an expert in the matter. As a result, nothing changes.

From a systems perspective, social influence not only includes individuals and groups, but can equally have power over norms and roles (French and Raven, 1959). This means that the chrono system can heavily influence all other system levels and disrupt the status quo.

The issue of environmental compatibility is another interesting element when highlighting the social influence findings. We see managers and practitioners conforming to supporting people in environments that are not compatible, which should actually test their ethics and values. However, what we find is conformity where staff do not make a true lasting change in their belief system, but rather accept the situation and comply (Kelman, 1958).

As the PBS Practice Framework is adopted, leaders and managers' opinions begin to change and we can see this in the language discourse (Appendix O: Addressing Toxic Environments) as language becomes ethical and principle bound. The practice framework is influencing a larger network of individuals within an organisation. This is very much a structural approach consistent with dynamic social impact theory. There is evidence of interpersonal influence in that the PBS practitioners are influencing attitudes and opinions of leaders. The PBS practitioners are considered experts by the leaders who in turn are influenced by this. What is also occurring is socialisation and professional identities are beginning to form. The leaders are weighing up the message and then integrating their opinions within the social structure. Norm opinions become rooted and this is where real change occurs.

Some practitioners, however, presented inequalities in influence and did not share the feelings, attitudes and behaviours in a positive sense. Although this was not explored in detail, from the research notes there appeared to be a sense of fear and trepidation from these practitioners. A number of these practitioners were long standing members of the team and held in high regard, therefore they were influential in group interactions and although equal in position had a perceived seniority. These individuals began to develop expectations for the future and in all cases were communicating messages that PBS was a fad and would phase out quickly. This phenomenon is consistent with Expectation States Theory described by Berger et al. (1980). As policy, practice and continuous professional development evolved, these individuals began to have less power and began to conform to the situation. Whether

their opinions truly changed is yet to be seen; however, what is evident is that practice, skill and knowledge transfer is occurring and is consistent with the ethics and principles of PBS.

7.4 Implications and Importance of the Findings for the Community of Practice

Here, I return to the focus and aim of the research in Chapter 2 in order to summarise my contribution to practice and theory and identify which parts are most significant in terms of enhancing quality of life for people with autism. I will also highlight the leadership and management practice standards that have been influenced by research and practice.

Firstly, this study was the first to consider PBS and autism practice in light of the ecological systems of Bronfenbrenner's theory. I set out to design, implement and disseminate a PBS practice framework for autism practitioners that was influenced by academic and social policy. Although there is a growing array of national guidance, the literature and findings demonstrated that interpretation remains a challenge for the community and the essence of PBS is lost once translated in practice.

This Practice Framework offers closure of the theory-practice gap in a workable framework that enables durable systems change within services at the heart of leadership and practice. It goes further in providing the community with practice standards and benchmark indicators that have been influenced by leadership and management theory. The significance of incorporating leadership and management theory as a central component is ensuring sustainability and ethical decision making that focuses on person-centred planning philosophy. To support the community further and to reduce the likelihood of abusive practices being encountered, governance approaches influence and maintain the integrity of the framework and have been considered under the umbrella of a systems theory perspective. As a result, this is a unique contribution to the community of practice and this research has integrated this framework across a national organisation that supports over 5,000 service users.

This study reinforces the vast array of research already undertaken, whilst also offering a unique insight into the interconnectedness issues of policy and how this is translated into practice. I have found no other study from a PBS or autism perspective that has attempted to do this. There are a number of significant factors that have already had an impact on the community and will continue to do so. These are:

- People with autism are living better quality of lives in terms of behaviour reduction, rights, occupation, health and wellbeing and medication reduction. It is

appropriate to conclude that crisis breakdown in services will therefore reduce the pressures on treatment and admission services. In this study, people with autism are seen to increase their opportunities and have a greater level of freedom due to the increased competencies and capabilities of support staff. This study has also assisted in reducing and adapting environmental toxic placements and, with informed decision making based on person-centred and clinical need, service users are able to remain at home in their own communities. Compatibility issues are not the focus of concern any longer. It is hoped that over time we will start to see a reduction in the cost of provision due to behaviour not being the component of high cost placements; although there will always be a need for this, the hope is that this framework can reduce the public spending in this area.

- The introduction of practice standards and benchmark indicators is significant in terms of application of the PBS principles. No other guidance offers instruction on how this practice should be embedded or what the impact on practice will look like. This will help leaders, managers and practitioners to know when the framework is correctly being practiced and the toolkit incorporated within the framework assists in maintaining an interconnected systems approach. This is unique to the community of practice. Researchers such as Mansell, Beadle-Brown, Emerson and Allen all advocate further research and practice guidance, which this study and Practice Framework offers.

- PBS entails many challenges, however, at the heart of this is how it has been mischaracterised over recent years. This is mainly due to supporters of applied behaviour analysis and members of the community stating that they follow a PBS approach when in fact they do not (LaVigna and Willis, 2012). This study and practice framework will offer further clarity on the philosophy and practice of PBS and particularly how it can be flexibly adopted within autism services.

- A further contribution to practice concerns ethical decision making. The framework has an ethical value base as an undercurrent within its practice. Seedhouse's (2009) ethical toolkit has been synthesised and included within the framework. This will contribute to ethical practice and the maintenance of rights-based approaches, particularly supporting person-centred planning.

- The theoretical perspective this study confirmed the findings of academics and researchers in the community and also in extended communities such as leadership and management. The discourse of decision making by practitioners on people with autism's lives was particularly illuminating. A power imbalance became evident, which was further extrapolated to uncover that the decisions being made were inconsistent with the ideologies within the community. The discourse that was created resulted in restrictive practices even though

practitioners stated they were opposed to these practices. This demonstrates that practitioners do not fully understand nor have the skills to implement the 'Valuing People Strategy' (2009). There is currently limited evidence on quality of life outcomes and this phenomenon may give rise to further research.

- The systems theory also offered further insight into the situation and the fact that the decisions being made at the micro level can be inconsistent with the policy drivers at the exo level. Synthesising this with the Practice Framework and benchmark indicators is unique in that it bridges the gap between policy and practice.

- Finally, this practice framework has been designed to consider the competencies and capabilities that have been lacking within the community of practice and it has been designed to consider regulation and the academic requirements that staff need to attain in their practices when completing their diplomas. This practice framework can now directly support practitioners in successfully completing these awards, whilst also demonstrating their skills within a robust and compliant regulation framework.

7.5 Limitations of the Research

The findings in any research will naturally have limitations and this study is no different. This was an ambitious and complex study to undertake and although great care and attention was taken to identify a clear scope for the research, the analysis of the social arenas established the vast complexity of the situation and any one strand could have been researched as a single entity. As a result, data collection processes were time consuming and lengthy. Thematic analysis (Bruan and Clarke, 2006) was adopted due to its flexibility, however, because of the complexity of the situation and the amount of data analysis, this was time consuming. Using qualitative data analysis software such as Ethnograph v.6 would have supported the development of code trees and facilitated searching for data more easily. Attaching memos and notes to text that are reminders to salient points of the research questions would have assisted in the findings and discussion chapters. Although this was a limitation, the study did not set out to achieve reliable data, but rather to create an interpretative and subjective account of the situation, which was achieved.

A further limitation that needs illuminating is that of the participant selection. An appreciation and critical thinking was not considered as in depth as it should have been into the socio-historical factors of the participants and their levels of knowledge and experience pertaining to their positions. This includes their professional qualifications and years of service. The social care industry is a moveable feast and those who have many years of service will have encountered numerous changing

philosophies of care and policy. Philosophical foundations in some cases were at odds with the current practices in today's community.

It was also evident in the study that many of the leaders and managers had not maintained their skill and knowledge level according to the current situation. As a result, knowledge was seriously lacking in both academic and social policy terms. The level of expected responses, particularly concerning policy awareness and responsibilities, was below an acceptable standard in compliance terms; therefore further time was required to train leaders and managers as an introduction to PBS leadership. Continuous efforts were required following implementation of the practice framework to ensure leaders and managers adopted all of the necessary systems due to their interconnectedness. Although this remained relevant to the aims of the research, time was costly here.

There were also a number of contrasting variables between practitioners. Attitudes were variable according to those that had more frequent supervision, support and training from their line managers and those who were engaged in more meaningful activity with management due their manager's style and approach to management. Practitioners who were more vocal tended to be those that had limited meaningful engagement with managers and leaders and who also had encountered historical changes in the field. As a result, attitudes were affected and some fragmented practice and processes were evident due to their belief that PBS was a fad. Leaders and managers were advised to ensure regular and close supervision of these practitioners to ensure the integrity of the process was maintained. To discount these attitudinal problems further, triangulation of responses was analysed according to the academic and policy literature, which helped to support the accuracy of the themes from interview transcripts and focus group sessions.

There are delimitations (Creswell, 2003) in the study that are worthy of mention here. The areas that were chosen in this research were firstly pertinent to the research aim and questions. They were, however, contextualised and expanded to incorporate a rich array of philosophies and theories to ensure that both a critical and in-depth account was taken. My embedded stance and positionality in this study has certainly influenced what has been chosen and excluded due to my role within the organisation. This was not considered a weakness in terms of this study, but rather a delimitation that was influenced by the epistemological and ontological stance. In addition, the range of data collection methods allowed for a comprehensive examination of the subjective realities of leaders, managers and practitioners, which offered similarity to my own experiences and further strengthened the rationale for the evidence chosen.

7.6 Recommendations for Future Research

As a result of the research and findings in this thesis, a number of key areas for future research can be identified and recommended. Firstly, the discussion chapter identified that there were time constraints to the study, therefore a further longitudinal study would be beneficial in order to establish the lasting impact the PBS Practice Framework has had on the community. This is twofold. It is firstly warranted to focus on the lifespan perspective of quality of life for people with autism and, secondly, to establish if systems change has continued to evolve in the organisation and practice and the influence this has made. The study can continue with situational analysis as its adopted methodological approach and return to capture how PBS has evolved in the community of practice after some time to consolidate.

In addition to this, further research is required into governance from a systems perspective due to limited research in the PBS community of practice. Reviewing the interconnectedness of policy alongside governance from a PBS perspective will help develop more robust systems. Understanding the longitudinal effects of governance from this study will help shape future practice and procedures in the field. In particular, this study did not account for any horizontal coordination of networks and this would be an interesting component to consider when establishing sustainability of a competent workforce and how this could contribute to the community of practice.

Finally, the findings illuminated the concept of the 'invisible culture', which is an interesting phenomenon to consider in terms of PBS practice and how this shapes the community of the future. Lessons need to be learned from these and particularly how they socially influence practice. The government and community focused largely on practice models and policy following on from Winterbourne View, however, it lost an opportunity to explore how invisible cultures were created and not challenged by members of the community. More research is necessary here and should be expanded to other communities of practice in order to contrast findings as this will help identify new concepts for consideration.

7.7 Conclusions

The outcome of any research should be to create new and interesting proposals for the community of practice. This study has answered the research questions, although further studies may undercover a more comprehensive understanding of the interconnectedness of different policy factors, as further work is required to truly understand this in terms of PBS and autism practice. However, whilst this thesis has generated a new practice framework as a result of academic research and social policy, it has also provided answers to some critical questions in the field from a systems theory viewpoint. The findings demonstrated much needed guidance for leaders, managers and practitioners, which has now been provided.

Whilst further theoretical questions can always be posed, attention must be given to ensuring that existing data, and the pragmatic implications of these data, are translated effectively into practice to ensure this research continues to make a contribution to practice. Given that this thesis was broadly motivated by the current PBS and autism need, it is imperative that the direction of any future work remains focused upon improving PBS capacity across the sector, whilst acknowledging that further theoretical questions can, and should, be generated. In ensuring that PBS and autism needs, along with theoretical understanding, remain closely entwined, successful research advances can be made that will improve the lives of people with autism and their support staff.

REFERENCES

Adair, J.E. (1973) *Action-Centred Leadership,* London: McGraw-Hill.

Allen, D. and Hardin, P. K. (2001) 'Discourse Analysis and Epidemiology of Meaning', *Nursing Philosophy,* 2, pp. 163-176.

Allen, D., James, W., Evans, J., Hawkins, S. and Jenkins, R. (2005) 'Positive behavioural support: Definition, current status and future directions', *Tizard Learning Disability Review,* vol. 10, no. 2, pp. 4–11.

Allen, D., Hawkins, S. and Cooper, V. (2006) 'Parents' use of physical interventions in the management of their children's challenging behaviour', *Journal of Applied Research in Intellectual Disabilities,* pp. 356-363.

Allen, D. (2009) *Ethical approaches to physical interventions,* 1st edition, Kidderminster: British Institute for Learning Disabilities.

Allen, D. (2011) *Reducing the Use of Restrictive Practices with People who have Intellectual Disabilities. A Practical Approach,* 1st edition, Kidderminster: British Institute for Learning Disabilities.

Allen, D., and Baker, P. (2012) 'Use of positive behaviour support to tackle challenging behaviour', *Learning Disability Practice* vol. 15, no.1, pp. 18-20.

Anderson, R. and Braud, W. (2011) *Transforming Self and Others through Research: Transpersonal Research Methods and Skills for the Human Sciences and Humanities,* Albany: State University of New York Press.

Anderson, C. M., and Freeman, K. A. (2000) 'Positive behavior support: Expanding the application of applied behavior analysis'. *The Behavior Analyst,* vol. 23, pp. 85 – 94.

Anderson, M. (2008) *Tales from the Table: Lovaas/ABA Intervention with Children on the Autistic Spectrum* .

Ando, H., and Yoshimura, I. (1979) 'Comprehension skill levels and prevalence of maladaptive behaviors in autistic and mentally retarded children'. *Child Psychiatry and Human Development,* vol. 9, pp. 131-136.

Arter, J. A., and Spandel, V. (1992) 'Using portfolios of student work in instruction and assessment'. *Educational Measurement: Issues and Practice,* vol. 11, no. 1, pp. 36-44.

Argyris, C. (1960) *Understanding Organisational Behaviour,* Illinois: The Dorsey Press Inc.

Autism Act 2009, London: HMSO.

Australian Psychological Society Ltd (2011) *Evidence-based guidelines to reduce the need for restrictive practices in the disability sector*, Australia: Australian Psychological Society.

Baker, D. J.. and Feil, E.G. (2000) 'A self-evaluation by agencies providing residential support regarding capacity to support persons with disabilities and challenging behaviors'. *International Journal of Disabilities,* no. 47, pp. 171-81.

Bamford, D. (2005) *Equal Lives: Review of Policies and Services For People with Learning Disabilities in Northern Ireland*. Review of Mental Health and Learning Disability: Northern Ireland.

Bates, P., and Silberman, W. (2007) *Modelling Risk Management in Inclusive Settings* [Online] London: National Development Team. Available from: http://www.ndt.org.uk/docsN/ET_SIrisk.pdf (accessed 21/05/2014).

Baumeister, A.A. (2004) *The meaning of mental retardation*. In: Greenspan S, Switzky H, editors. What is mental retardation? *(*chap. 7, book on CD*)* Washington, DC: AAMR Disability Books Online; 2004.

BBC (2011) *Undercover Care: the Abuse Exposed To Vulnerable People in Winterbourne View Hospital*. BBC Panorama first shown Tuesday 31 May 2011, London: BBC.

Beadle-Brown, J., Murphy, G., and DiTerlizzi, M. (2008) 'Quality of Life for the Camberwell Court', *Journal of Applied Research in Intellectual Disabilities, vol.* 22, no.4, pp. 380 – 390.

Beadle-Brown, J., Hutchinson, A. and Whelton, B. (2012) 'Person-Centred Active Support - Increasing Choice, Promoting Independence and Reducing Challenging Behaviour', *Journal of Applied Research in Intellectual Disabilities* [Online], vol. 25, pp**.** 291-307. Available at: http://dx.doi.org/10.1111/j.1468-3148.2011.00666.x.

Beadle-Brown, J., Mansell, J., Ashman, B., Ockenden, J., Iles, R., and Whelton, B. (2014) 'Practice leadership and active support in residential services for people with intellectual disabilities: an exploratory study', *Journal of Intellectual Disability Research*, vol. 58, no.9, pp. 838-850.

Berger, J., Rosenholtz, S. J., and Zelditch, M. Jr. (1980) 'Status Organising Process'. *Annual Review of Sociology*, no. 6, pp. 479-508.

Blatt, B., and Kaplan, F. (1974) *Christmas in purgatory: A photographic essay on mental retardation*, New York: Center on Human Policy Press.

Bhaumik, S., Branford, D., McGrother, C., & Thorp, C. (1997) 'Autistic traits in

adults with learning disabilities', *The British Journal of Psychiatry,* no. 170. pp. 502-506.

Bradley, E., Summers, A., Wood, H.L. and Bryson, S.E. (2004) Comparing rates of psychiatric and behaviour disorders in adolescents and young adults with severe intellectual disability with and without autism *Journal of autism and developmental disorders,* vol. 34, no.2, pp. 151-161.

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology, vol. 3. No. 2, pp. 77–101, (Online), Available: http://www.informaworld.com/smpp/content~db=all~content=a795127197~frm=titlelink.

British Institute for Learning Disabilities (2001, 2006, 2010 & 2014) *Code of Practice for minimizing the use of restrictive physical interventions: planning, developing and delivering training. A guide for purchases of training, training organisations and trainers*, Kidderminster, UK: BILD.

Bonner, G., Lowe, T., Rawcliffe, D., and Wellman, N. (2002) 'Trauma for all: a pilot study of the subjective experience of physical restraint for mental health inpatients and staff in the UK', *Journal of Psychiatric and Mental Health Nursing*, vol. no. 4, pp. 465–473.

Boucher, J. (2011) 'The Autistic Spectrum: Characteristics, Causes, and Practical Issues', *Journal of Autism & Development Disorders,* vol. 41, no. 12, pp. 271 - 274.

Bronfenbrenner, U. (1979) *The ecology of human development: Experiments by Nature and Design*, 1st edition, Cambridge, Massachusett and London: Harvard University Press.

Brugha, T., McManus, S., Meltzer, H., Smith, J., Scott F, J., Purdon S., Harris J., and Bankart, J. (2007) *Autism Spectrum Disorders in adults living in households. Report from the Adult Psychiatric*, England: National Centre for Social Research, the Department of Health Sciences, University of Leicester, and the Autism Research Centre, University of Cambridge.

Brugha, T., Cooper, S. A., McManus, S., Purdon, S., Smith, J., Scott, F., J, Spiers, N., and Tyrer, F. (2012) *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey,* England: The NHS Information Centre for Health and Social care by the University of Leicester, the Leicestershire Partnership NHS Trust, the National Centre for Social Research, and the University of Glasgow.

Bullard, L., Fulmore, D., and Johnson, K. (2003) *Reducing the Use of Restraint and Seclusion. Promising Practices and Successful Strategies*, 1st edition, Washington: CWLA Press.

Burg, M. M., Reid, D. H., and Lattimore, J. (1979) 'Use of a self-recording and supervision program to change institutional staff behavior'. *Journal of Applied Behavior Analysis.* no. 12, pp. 363 – 375.

Butler, I. (2002) 'A Code of Ethics for Social Work and Social Care Research', *The British Journal of Social Work*, vol. 32, no. 2, pp. 239-248.

Campbell, A. V., Chin, J. and Voo, T. C. (2007) 'How can we know that ethics education produces ethical doctors?' *Medical Teacher*, no. 29, pp. 431-436.

Care Act (2016), London: HMSO.

Charmaz, K. (2000). Constructivist and objectivist grounded theory. In N. K. Denzin & Y. Lincoln (Eds.) *Handbook of qualitative research* (2nd edition pp. 509–535). Thousand Oaks, CA: Sage.

Carr, E. G., Horner, R. H., and Turnbull, A. P. (1999) *Positive Behavior Support for People with Developmental Disabilities: A research synthesis*. Washington, DC: American Association on Mental Retardation.

Carr, E, G., Dunlap, G., Horner, R, H., and Koegel, R, I. (2002) 'Positive Behaviour Support: Evolution of an Applied Science', *Journal of Positive Behaviour Interventions*, vol. 4, no. 1, pp. 4-16.

Carr, E. G. (2007) 'The expanding vision of positive behavior support: Research perspectives on happiness, helpfulness, hopefulness', *Journal of Positive Behaviour Interventions*, vol. 9, no. 1, pp. 3-14.

Carrithers, M., Collins, S., and Lukes, S. (1985) *The category of the person - Anthropology, philosophy, history*, Cambridge, United Kingom: Cambridge University Press.

Charter of Human Rights & Responsibilities (2006): Victoria, Australia.

Chowdhury, M., and Benson, B, A. (2012) 'Use of differential reinforcement to reduce behavior problems in adults with intellectual disabilities: a methodological review. Use of differential reinforcement to reduce behavior problems in adults with intellectual disabilities: a methodological review*', Journal of Developmental and Physical Disabilities*, vol. 8, no. 4, pp. 256-265.

Clarke, A, E. (2005) *Situational Analysis. Ground Theory After the Postmodern Turn*, 1st edition, London: Sage.

Clarke, A., and Star, S, L. (2008) *The social worlds framework: A theory/methods package*. In Edward Hackett, Olga Amsterdamska, Michael Lynch & Judy Wajcman (Eds.), The handbook of science and technology studies (pp.113-139). Cambridge, Massachusetts: The MIT Press.

Coffey, G. W. (2010) *A systems approach to Leadership: how to create sustained high performance in a complex and uncertain environment.* Heidelberg: Springer.

Colton, D. (2004) *Checklist for assessing your organization's readiness for reducing seclusion and restraint.* Unpublished paper. Staunton, VA: Commonwealth Center for Children and Adolescents.
Available: http://rccp.cornell.edu/pdfs/SR%20Checklist%201-Colton.pdf

Colton, D. (2008) Leadership's and program's role in organizational and cultural change to reduce seclusions and restraints. In M. A. Nunno, D. M. Day., and L. B. Bullard. (Eds.) *For our own safety: Examining the safety of high-risk interventions for children and young people* (pp. 143–166). Arlington, VA: Child Welfare League of America.

Connelly, L. M. (2009) 'Mixed Methods Studies', *MEDSURG Nursing*, vol. 1, no. 18, pp. 31.

Creswell, J. W. (2003) *Research design: Qualitative, quantitative, and mixed methods approaches*, 2nd edition, Thousand Oaks, CA: Sage.

Creswell, J. W., and Clark, P. (2007) *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage Publications.

Crone, D. A., and Horner, R. H. (2003) *Building positive behavior support systems in schools*. New York, London: Guilford Press.

Crone, D. A., Hawken, L. S., and Bergstrom, M. K. (2006) *A demonstration of training, implementation, and use of functional behavioral assessment in ten elementary and middle school settings*. Manuscript submitted for publication.

Cummins, R.A., McCabe, M.P., Romeo, Y., Reid, S., and Waters, L. (1997) 'An initial evaluation of the Comprehensive Quality of Life Scale – Intellectual Disability'. *International Journal of Disability, Development and Education*, no. 44, pp. 7-19.

Denckla, M. B. (1986) Editorial: New diagnostic criteria for autism related behaviour disorders.

Denscombe, M. (2010) *The Good Research Guide: for small-scale social research*, 4th edition, Maidenhead: Open University Press.

Department of Education (1997) *Individuals with Disabilities Education Act*, United States of America: Department of Education.

Department of Health (2001) *A new strategy for learning disabilities for the 21st century*, London: Department of Health.

Department of Health and Department for Education and Skills (2002) *Guidance for Restrictive Physical Interventions: How to provide safe services for people with learning disabilities and autistic spectrum disorders*, London: HMSO.

Department of Health (2005) R*esearch Governance Framework for Health and Social Care*. London: HMSO.

Department of Health (2007) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs*: Report of a Project Group, revised edition, London: Department of Health.

Department of Health (2009) *Valuing People Now: a new three year strategy for people with learning disabilities*, London: Department of Health.

Department of Health (2010) *Fulfilling and rewarding lives. The strategy for adults with autism in England*, London: Department of Health.

Department of Health (2012a) *Winterbourne View Review: Concordat*, London: Department of Health.

Department of Health (2012) *Estimating the prevalence of autistic spectrum conditions in adults*, London: Department of Health.

Department of Health (2012b) *Transforming Care: a national response to Winterbourne View Hospital*, London: Department of Health.

Department of Health (2014) *Positive and Proactive Care: reducing the need for restrictive interventions*, London: Department of Health.

Department of Health (2014) *Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update*, London: Department of Health.

Department of Human Services (2009) *Physical restraint in disability services*. Melbourne: Office of the Senior Practitioner.

Department of Human Services (2010) *Other restrictive interventions: locked doors, cupboards, other restrictions to liberty and practical ideas to move away from these practices*, Australia: Office of the Senior Practitioner, Victorian Government Initiative.

Department of Human Services (2011) *Positive Practice Framework: A guide for behaviour support Practitioners*, Australia: Victoria Government.

Deprivation of Liberty Safeguarding (2007), London: HMSO.

Deveau R., and McGill P. (2007) *As the last resort: reducing the use of restrictive physical interventions.* Canterbury: Tizard Centre.

Deveau, R., and McGill, P. (2009) 'Physical interventions for adults with intellectual disabilities: survey of use, policy, training and monitoring', *Journal of Applied Research in Intellectual Disabilities,* vol. 22, no. 1, pp. 145-151.

Deveau, R., and McGill, P. (2014) Leadership at the frontline: impact of practice leadership management style on staff experiences in services for people with intellectual disability and challenging behaviour. *Journal of Intellectual and Developmental Disability*, vol. 39, no. 1, pp. 65-72.

Disability Discrimination Act (1995), London: HMSO.

Disability Services Act (2006), Queensland Government, Australia.

Disabilities Services Commission (2014) *Code of Practice for the Elimination of Restrictive Practice*, Australia: Government of Western Australia.

Dunham, R, B. and Pierce, J, L. (1989) *Management*, United States of America: Scott Foresman and Co.

Dunlap, G., Hieneman, M., Knoster, T., Fox, L., Anderson, J., & Albin, R.W. (2000) 'Essential elements of in-service training in positive behavioral support', Journal of Positive Behavior Interventions, 2(1), pp. 22-32.

Dunlap G. (2006) 'The applied behavior analytic heritage of PBS: A dynamic model of action-oriented research'. *Journal of Positive Behavior Interventions,* no.8, pp. 58–60.

Dunlap, G., Carr, E. G., Horner, R. H., Zarcone, J. R., and Schwartz, I. (2008) 'Positive behavior support and applied behavior analysis: A familial alliance', *Behaviour Modification*, vol. 32, no. 1, pp. 682-698.

Dunlap, G, Sailor, W, Horner, R.H, and Sugai, G. (2009) 'Overview and history of positive behaviour support. In W. Sailor, G. Dunlap, G. Sugai, and R. Horner (Eds.).

Dunlap, G., & Kincaid, D. (2014) *The definition of positive behaviour support: Moving toward greater precision*. Featured presentation at the 11th International Conference of the Association for Positive Behavior Support, Chicago, IL.

Dunlap, G., Kincaid, D., Horner, R. H., Knoster, T., and Bradshaw, C. P. (2014) 'A comment on the term "positive behaviour support', *Journal of Positive Behavior Interventions*, vol. 16, no. 1, pp. 133-136.

Economic and Social Research Council (2015) *ESRC Framework for research ethics*, UK: Economic and Social Research Council.

Emerson, E. (1992) 'Self injurious behaviour: an overview in recent trends in epidemiological and behavioural research', *Mental Handicap Research*, vol. 4, no. 1, pp. 49-81.

Emerson, E. (2001) *Challenging behaviour: analysis and interventions in people with learning difficulties*, 2nd edition, Cambridge: Cambridge University Press.

Emerson, E. (2003) 'Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability', *Journal of Intellectual Disability Research*, vol. 47, no. 1, pp. 51-58.

Emerson, E. and Stancliffe, R. J. (2004) 'Planning and action: comments on Mansell and Beadle-Brown', *Journal of Applied Research in Intellectual Disabilities*, vol. 17, no. 1, pp. 23–6.

Emerson, E., and Baines, S. (2007) *Health Inequalities & People with Learning Disabilities in the UK: 2010*, London: Learning Disabilities Observatory.

Emerson, E., Copeland, A., and Glover, G. (2011) 'The uptake of health checks for adults with learning disabilities in England: 2008/9 - 2011/12', *Tizard Learning Disability Review*, vol. 18, no, pp. 45-49.

England, K, V, L. (1994). Getting personal: Reflexivity, positionality, and feminist research. *The Professional Geographer*, vol. 46, no. 1, pp, 80-89.

Forsyth, D. R. (2014). *Group dynamics*, 6th edition. Belmont, CA: Wadsworth Cengage Learning. Foucault. (1973) The Order of Things.

French, J. R. P., Jr (1956) 'A Formal Theory of Social Power'. *Psychology Review*, no. 63, pp, 181-94.

Fulton, J., Kuit, J.A., Sanders, G., and Smith, P. (2013) "The Professional Doctorate: A Practical Guide for Students". Basingstoke: Palgrave Macmillan.

General Social Care Council (2001) *Code of Practice for Social Care Workers and Code of Practice for Employees of Social Care Workers.* [Online]. Available: *https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/229049/0234.pdf* (Accessed: 3rd September 2014).

Glaser, B. & Strauss, A. L. (2012) *Discovery of Grounded Theory: Strategies for Qualitative Research*, 7th edition, London: Aldine Transaction.

Golafshani, N. (2003) 'Understanding Reliability and Validity in Qualitative Research'. *The Qualitative Report*, vol. *8*, no. 4, pp. 597-606. Retrieved from http://nsuworks.nova.edu/tqr/vol8/iss4/6

Government of South Australia (2013) *A framework for recognition & management of challenging behaviour*, South Australia: Government of South Australia.

Gresham, F. M. (2003) 'Establishing the technical adequacy of functional behavioral assessment: Conceptual and measurement challenges'. *Behavioral Disorders*, no. 28, pp. 282-298.

Grey, I. M., and McClean, B. (2007) 'Service user outcomes of staff training in positive behaviour support using person-focused training: a control group study'. *Journal of Applied Research in Intellectual Disabilities,* no. 20, pp. 6–15.

Healthcare Commission (2005) *Review of Policy and Services for People with a Learning Disability in Northern Ireland. Review of Learning Disability and Mental Health*, Northern Ireland: Northern Ireland Assembly.

Healthcare Commission (2006) *Joint Investigation into Services for People with Learning Disabilities at Cornwall Partnership NHS Trust*, London: Healthcare Commission.

Healthcare Commission (2007) *Investigation into the Service for People with Learning Disabilities.* Provided by Sutton and Merton Primary Care Trust, London: Healthcare Commission.

Health & Social Care Act (2015), London: HMSO.

Herzberg, F., Mausner, B., and Synerman, B. (2010) *The Motivation to Work*, 12th edition, United States of America: Transaction Publishers.

Horner, R. H., Dunlap, G., Koegel, R.L, Carr E.G., Sailor, W., and Anderson J. (1990) 'Toward a technology of "non-aversive" behavior support. *Journal of the Association for Persons with Severe Handicaps*, vol. 15, no. 1, pp. 125-132.

Horner, R.G., Carr, E.G., and Strain, P.S. (2000) 'Problem behavior interventions for young children with autism: a research synthesis'. *Journal for Autism & Developmental Disorders*, no. 32, pp. 423–446.

Howlin P., Goode, S., Hutton, J., and Rutter M. (2004a) Adult outcomes for children with autism. *Journal of Child Psychology and Psychiatry*, vol. 45, no. 2, pp. 212-229.

Huckshorn, K A. (2004) 'Reducing seclusion and restraint use in mental health settings. Core strategies for prevention', *Journal of Psychosocial Nursing*, vol. 42, no. 9, pp. 22-33.

Huckshorn, K A. (2005) *Six Core Strategies to Reduce the Use of Seclusion and Restraint Planning Tool*, Alexandria, VA: National Technical Assistance Centre.

Human Rights Act (1998), London: HMSO.

Institute for Public Care (2012) *Leading the Way: The Distinctive Contribution of the Not-for-Profit Sector in Social Care*, England: Oxford Brookes University.

Individuals with Disabilities Education Act (1997), United States of America.

Jaworski, A., and Coupland, N. (1999) *The Discourse Reader*. London: Routledge.

Jones, E., Felce, D., Lowe, K., Bowley, C., Pagler, J., Strong, G., Gallagher, B., Roper, A., and Kurowska, K. (2001) 'Evaluation of the dissemination of active support training and training trainers'. *Journal of Applied Research in Intellectual Disabilities,* vol. *14*, no. 2, pp. 79-99.

Jones E., Lowe, K., Brown, S., Albert, L., Saunders, C., Hake, N., and Leigh, H. (2013). 'Active Support as a primary prevention strategy for challenging behaviour*'. BILD International Journal of Positive Behavioural Support,* vol. 3, no. 1, pp.16- 30.

Johnson, R. B., Onwuegbuzie, A. J. and Turner, L. A. (2007) 'Toward a definition of mixed methods research'. *Journal of Mixed Methods Research,* vol. *1*, no 2, pp.112-133.

Jordan, A., Wurzel, R. K.W., and Zito, A. (2005) 'The rise of 'new' policy instruments in comparative perspective: Has governance eclipsed government?', *Political Studies Association Journal*, vol. 53, no.3, pp. 457–651.

Joseph Rowntree Foundation (2006) *Person-centred planning in social care: A scoping review*, York, UK: Joseph Rowntree Foundation.

Kamps, D., Wendland, M., and Culpepper, M. (2006) 'Active teacher participation in functional behaviour assessment for students with emotional and behavioral disorders risks in general education classrooms'. *Behavioral Disorders,* vol. 31, pp. 128-146.

Kaplan, B., and Maxwell, J. A. (1994) *Qualitative Research Methods for Evaluating Computer Information Systems*. In J. G. Anderson, C. E. Aydin, & S. J. Jay (Eds.), Evaluation Health Care Information Systems: Methods and Application. California: Sage Publications.

Kashima, Y., and Foddy, M. (2002) Time and self: The historical construction of the self. In Yoshihisa Kashima, Margaret Foddy & Michael Platow (Eds.), *Self and identity: Personal, social and symbolic* (pp.181-206). New Jersey: Lawrence Erlbaum Associates, Publishers.

Kelman, H, C. (1958) 'Compliance, identification, and internalization: Three processes of attitude change', *Journal of Conflict Resolution,* vol. 2, no.1, pp. 51-60.

Kincaid, D., Dunlap, G., Kern, L., Lane., K L., Bambara, L M., Brown, F., Fox, L,. and Knoster, T P. (2015) 'Positive Behaviour Support: A Proposal for Updating and Refining the Definition', *Journal of Positive Behavior Interventions,* vol 18. No. 2, pp. 69-73.

Kincaid, D., and Dunlap, D. (2015) T*he definition of positive behaviour support: Moving toward greater precision*. Paper presented at the 12th International Conference of the Association for Positive Behavior Support, Boston, MA.

Knapp, M., Romeo, R., and Beecham, J. (2007) 'The Economic Consequences of Autism in the UK', *Autism Journal*, vol.13, no. 3, pp.317-336.

Knoster, T., Anderson, J., Carr, E. G., Dunlap., G., and Horner, R, H. (2003) Emerging challenges and opportunities: Introducing the Association for Positive Behavior Support. *Journal of Positive Behavior Interventions,* no. 5, pp.183–186.

Kouzes, J. M., Posner, B. Z. (2012) *The Leadership Challenge: how to make extraordinary things happen in organisations*, 5th edition, San Francisco: Wiley.

Krippendorff, K. (2013) Content Analysis: An Introduction to Its Methodology , 3rd edition, SAGE, Los Angeles.

Lave, J., and Wenger, E. (1991) *Situated learning: Legitimate peripheral participation*, Cambrindge, England: Cambridge University Press.

LaVigna, G W., and Willis, T J. (2012) 'The efficacy of positive behavioral support with the most challenging behaviour: The evidence and its implications', *Journal of Intellectual & Developmental Disability*, vol. 37, no.3, pp. 185-195.

Lovett, H. (1996) *Learning to Listen: Positive approaches and people*, 1st edition, Baltimore: Paul H Brookes Publishing Company.

Lucyshyn, J.M., Dunlap, G., and Albin, R.W. (2002) *Families and positive behavior support: Addressing problem behavior in family contexts*. Baltimore: Paul H. Brookes. Google Scholar.

Lucyshyn, J. M., Albin, R. A., Horner, R. H., Mann, J. C., Mann, J. A., and Wadsworth, G. (2006) *Family implementation of positive behavior support with a child with Autism: A longitudinal, single case experimental and descriptive replication and extension*. Manuscript submitted for publication.

Lucyshyn, J. M., Dunlap, G., and Freeman, R. (2015) *A historical perspective on the evolution of positive behaviour support as a science-based discipline*. In F. Brown, J. Anderson, & R. DePry (Eds.), *Individual positive behaviour supports: A standards-based guide to practices in school and community-based settings* (pp. 3–25). Baltimore, MD: Paul H. Brookes.

Luiselli, J. K., Putnam, R. F., and Sunderland, M. (2002) 'Longitudinal evaluation of behavior support intervention in a public middle school'. *Journal of Positive Behavior Interventions*, no. 4, pp. 182-188.

Mansell, J. (1994) 'Specialized group homes for persons with severe or profound mental retardation and serious problem behaviour in England', *Research in Developmental Disabilities*, vol. 15, no. 5, pp. 371-388.

Mansell, J., and Beadle-Brown, J. (2004a) Person-centred planning or person-centred action? A response to the commentaries. *Journal of Applied Research in Intellectual Disabilities*, no. 17, pp. 31-35.

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

Mansell, J. (2010) *Raising our Sights: Services for adults with profound intellectual and multiple disabilities*, Kent: University of Kent.

Matson, J. L., and Shoemaker, M. (2009) 'Intellectual disability and its relationship to autism spectrum disorders', *Research in Development Disabilities,* vol. 30, no. 6, pp. 1107 -14.

Maxwell, T. W., and Kupczky-Romanczuk, G. (2009) 'The professional doctorate: defining the portfolio as a legitimate alternative to the dissertation' ', *Innovations in Education and Training International,* vol. 46, no. 2, pp. 135-145.

McClean, B., Grey, I, M., and McCracken, M. (2007) 'An evaluation of positive behavioural support for people with very severe challenging behaviours in community-based settings', *Journal of Learning Disabilities*, vol. 11, no. 3, pp. 281-301.

McClintock, K., Hall, S., and Oliver, C. (2003) 'Risk markers associated with challenging behaviours in people with intellectual disabilities: a meta-analytic study'. *Journal of Intellectual Disability Research*, no. 47, pp. 405-416.

McGill, P. Murphy G., & Kelly-Pike A. (2009) 'Frequency of Use and Characteristics of People with Intellectual Disabilities subject to Physical Interventions', *Journal of Applied Research in Intellectual Disabilities*, vol. 22, no. 1, pp. 152-158.

McGill, P., and Toogood, S. (1994) *Organising Community placements in Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (eds) Emerson, McGill, P, and Mansell, J. London. Chapman & Hall.

McGinty, R., and Salokangas, M. (2014) 'Introduction: 'embedded research' as an approach into academia for emerging researchers', *Management in Education,* vol. 28, no.1, pp. 3-5.

McLuhan, M. (1995) *Understanding Media*: The Extension of Man. Cambridge, MA: The MIT Press.

McShane, S., and Von Glinow, M. (2010) *Organizational Behavior*, 3rd edition, United States of America: McGraw-Hill Education.

Mental Capacity Act (2005), London: HMSO.

Meissner, W., Ullrich, K. and Zwacka, S. (2006) 'Benchmarking as a tool of continuous quality improvement in postoperative pain management'.

Magito McLaughlin, D., Spinosa, T. R., and Marsalis, M. (2002) *Overcoming the barriers: Moving toward a service model that is conducive to person-centered planning*. In Holburn, S. & Veitz, P. (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 127-150). Baltimore: Paul H. Brookes.

Morris, J. (2005) *Children on the edge of care: Human Rights and the Children Act*, York.

Jonsen, A, R., Siegler, M., and Winslade, W, J. (2010) *Clinical ethics: a practical approach to ethical decisions in clinical medicine*, 7th edition, New York: New York: McGraw-Hill Medical.

National Center for the Dissemination of Disability Research (2005) 'What is Knowledge Translation?' *Focus*, (10), pp. 1-4 [Online]. Available at: *http://www.ncddr.org/kt/products/focus/focus10/* (Accessed: 3rd September 2015).

National Institute for Health & Care Excellence (2013) *Autism: the management and support of children and young people on the autism spectrum*, London: National Institute for Health & Care Excellence.

National Institute for Health & Care Excellence (2015) *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*, London: National Institute for Health & Care Excellence.

Needham, H., & Sands, N. (2010) Post-seclusion debriefing: A core nursing intervention. Perspectives in Psychiatric Care, 46, 221–233, http://dx.doi.org/10.1111/j.1744-6163. 2010.00256.x (PPC256 pii).

Noell, G. H., Duhon, G. J., Gatti, S. L., and Connell, J. E.(2002) Consultation, follow-up, and behavior man-agement intervention implementation in general edu-cation. *School Psychology Review*, no. 31, pp. 217-234.

Noell, G. H., Witt, J. C., Slider, N. J., Connell, J. E., Gatti, S. L., and Williams, K. L. (2005). Treatment implementation following behavioral consultation in

schools: a comparison of three follow-up strategies. *School Psychology Review,* no. 34, pp. 87-106.

Nunno, M A., and Mohr, W K. (2011) 'Black Box Restraints: The Need for Full Disclosure and Consent.', *Journal of Child & Family Studies* , vol. 20, no. 1, pp. 38-47.

Orme, J., and Shemmings, D. (2010) *Developing Research Based Social Work Practice,* London: Palgrave.

Osborne, J. G. (2005) *Person-centered planning: A faux fixe in the service of humanism*. In J.W. Jacobson, R. M. Foxx, & J. A. Mulick (Eds.), *Controversial therapies for developmental disabilities*: *Fads, fashion, and science in professional practice* (pp. 313– 329). Mahwah, NJ: Erlbaum.

Paley, S. (2008) *Use of mechanical devices: restrictive physical interventions, Principles for Practice.* Kidderminster: BILD Publications.

Paley, S. (2012) *Promoting Positive Behaviour when Supporting People with a Learning Disability and People with Autism*, London: Sage/Learning Matters/BILD.

Paterson. B. & Leadbetter D. (1998) Restraint and sudden death from asphyxia. *Nursing Times* vol.94, no. 44, pp. 62–64.

Paterson, B., Bradley, P., Stark, C, Saddler, D., Leadbetter, D., and Allen, D. (2003) 'Deaths Associated with Restraint Use in Health and Social Care In the UK: The Results of A Preliminary Survey', *Journal of Psychiatric and Mental Health Nursing,* no. 10, pp. 3-15.

Paterson, B., and Stubbs, B. (2011) 'Physical restraint in mental health services: a gap in the knowledge regarding this extreme manual-handling task', *Ergonomics,* vol. 59, no. 9, pp. 876-878.

Polanyi, K. (2001) *The great transformation: the political and economic origins of our time,* 2nd edition, Boston, USA: Beacon Press.

Pollard, R., Yanasak, E.V., Rogers, S.A., Tapp, A. (2007) 'Organizational and unit factors contributing to reduction in the use of seclusion and restraint procedures on an acute psychiatric inpatient unit'. *Psychiatric Quarterly*, no. 78, pp. 73-81.

Power, M. (2004) *The Risk Management of Everything; Rethinking The Politics of Uncertainty*. London: Demos.

Provan, K G., & Kenis, P. (2008) Modes of network governance: Structure, management, and effectiveness. *Journal of Public Administration Research and Theory,* no. 18, pp. 229–52.

Rankin, J., Regan, S. (2004) *Meeting complex needs in social care, housing, care and support*, London: Turning Point & Institute for Public Policy Research.

Reid, K., Flowers, P., and Larkin, M. (2005) Exploring the lived experience. *The Psychologist*, vol. 18, pp. 20–23.

Richards, C., Oliver, C., Nelson, L., and Moss, J. (2012) 'Self-injurious behaviour in individuals with autism spectrum disorder and intellectual disability', *Journal of Intellectual Disability Research*, vol. 56, no. 5, pp. 476-489.

Riessman, C.K. (2002) *Doing justice: Positioning the interpreter in narrative work*, in W. Patterson (ed), *Strategic Narrative: New Perspectives on the Power of Personal and Cultural Storytelling*, Lanham MA and Oxford UK, Lexington Books, (2002), pp.195-216.

Rimland, M. (1965) *Infantile autism: The syndrome and its implications for a neural theory of behaviour*. London: Methuen.

Robertson J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P., and Joyce, T. (2005) *The Impact of Person Centred Planning*. Institute for Health Research, Lancaster University.

Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007) *Challenging behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*, London: College Report CR144.

Rubin, H, J. & Rubin, I, S. (2005) *Qualitative Interviewing - Art of Hearing Data*, 2nd edition, London, New York: Sage Publications.

Rutter, M. (1978) Diagnosis and definition. In M. Rutter & E. Schopler (Eds.) *Autism: A Reappraisal of Concepts and Treatment* (pp.1-25). New York: Plenum Press.

Ryan, R., & Happell, B. (2009) 'Learning from experience: Using action research to discover consumer needs in post-seclusion debriefing'. *International Journal of Mental Health Nursing*, no. 18, pp. 100-107.

Sailor, W., and Paul, J, L. (2004) 'Framing positive behavior support in the ongoing discourse concerning the policies of knowledge'. *Journal of Positive Behavior Interventions*, no. 6, pp. 37- 49.

Sanderson, H. (2003) 'Implementing person-centred planning by developing person-centred teams', *Journal of Integrated Care*, vol. 11, no. 3, pp. 18–25.

Scheerenberger, R. C. (1981) Public residential facilities: Status and trends. *Mental Retardation*, vol. 19, no. 2, 59–60.

Schien, Edgar H. (1965), Organisational Psychology, Engelwood Cliffs, N.J.

Scott, T. M., Bucalos, A., Liaupsin, C., Nelson, C. M., Jolivette, K., and DeShea, L. (2004) 'Using functional behavior assessment in general education settings: Making a case for effectiveness and efficiency'. *Behavioral Disorders*, no. 29, pp. 189-201.

Scottish Executive Social Research (2007) *A Literature Review on Multiple and Complex Needs*, Scotland: Social Justice.

Seedhouse, D. (2005b). *Values based decision making for the caring professions*. Wiley: Chichester.

Seedhouse, D. (2009). '*Ethics: The heart of health care', 3rd* edition, Wiley, Chichester.

Senge, Peter. (1990) *The Fifth Discipline: the Art and Practice of the Learning Organization*. New York: Doubleday.

Seroussi, K., (2002) *Unravelling the Mystery of Autism and Pervasive Developmental Disorder: A Mother's Story of Research & Recovery*. New York: Broadways Books.

Shaw, I. (2008) 'Ethics and the Practice of Qualitative Research', *Sage Journal*, vol. 7, no. 4, pp. 400-414 .

Silverman, D. (2013). *Doing Qualitative Research*, 4th edn., London: Sage.

Skills for Care and Skills for Health (2014) *Positive and Proactive Workforce: A guide to workforce development for commissioners and employers seeking to minimise the use of restrictive practices in social care and health*, Skills for Health & Skills for Care, Leeds: Department of Health.

Smith, J.A., Flowers, P., and Larkin, M. (2009) *Interpretative phenomenological analysis: Theory, method and research*, London: Sage.

Stolz, S. B. (1977) Why no guidelines for behavior modification? *Journal of Applied Behavior Analysis*, no. 10, pp. 541–547.

Strauss, A., and Corbin, J. (1998) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, Second Edition. Thousand Oaks, CA: Sage.

Strauss, A., and Corbin, J. (1994) Grounded theory methodology: An overview. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273-285). Thousand Oaks, CA: Sage.

Sturney, P. & Palen McGlynn, A. (2002) Restraint Reduction. In D. Allen editor. *Ethical approaches to physical interventions.* Kidderminster, BILD publications.

Telzrow, C. F., and Beebe, J. J. (2002) *Best practices in facilitating intervention adherence and integrity*. In A. Thomas & J. P. Grimes (Eds.), *Best practices in facilitating interventions adherence and integrity* (pp. 503-516). Bethesda, MD: National Association of School Psychologists.

The Canadian Institutes of Health Research. (2005) *Developing a CIHR framework to measure the impact of health research* (cihr synthesis report). Accessed: September 7, 2015, from http://www.cihr-irsc.gc.ca/ e/30324.html.

The Faculty of Medical Leadership and Management. (2015) The King's Fund and The Center for Creative Leadership. *Leadership and Leadership Development in Health Care: The Evidence Base*, London, UK: The Faculty of Medical Leadership and Management with The King's Fund and the Center for Creative Leadership.

Totsika, V., Toogood, S., Hastings, R., and McCarthy, J. (2010) 'The effects of active support interactive training on the daily lives of adults with an intellectual disability. ', *Journal of Applied Research in Intellectual Disabilities*, vol. 23, no. 2, pp. 112-121.

Totiska, V., Hastings, R. P., Emerson, E., Lancaster, G. A., and Berridge, D. M. (2011) 'A population-based investigation of behavioural and emotional problems and maternal mental health: associations with autism spectrum disorder and intellectual disability. '*Journal of Child Psychology and Psychiatry*, vol. 51, no. 1, pp. 91-99.

Towell, D., and Sanderson, H. (2004) 'Person-centred planning in its strategic context: reframing the Mansell and Beadle-Brown critique', *Journal of Applied Research in Intellectual Disabilities*, vol. 17, no. 1, pp. 17–22.

Welsh Assembly Government (2001) *Fulfilling the Promises: Proposals for a Framework for People with Learning Disabilities*, Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2007) *Framework for Restrictive Physical Interventions Policy and Practice*, Cardiff: Welsh Assembly Government.

Wenger, E. (2004) 'Knowledge management as a doughnut: Shaping your knowledge strategy through communities of practice', *Ivey Business Journal*, Jan/Feb, pp. 1-8.

Wenger, E. (2010) Communities of practice and social learning systems. Accessed July 5, 2015, from http://wenger-trayner.com/resources/publications/cops-and-learning-systems/

West, M., Armit, K., Loewenthal, L., Eckert, R., West, T., and Lee, A. (2015) *Leadership and leadership development in health care: The evidence base. Faculty of Medical Leadership and Management*, The Centre for Creative Leadership, London: The King's Fund.

Wheatley, M., and Frieze, D. (2010) Leadership in the Age of Complexity: From Hero to Host. *Resurgence Magazine*, Winter 2011.

Wilkinson, L A. (2013) *Aggression in Autism Spectrum Disorders. Living with Autism*. http://livingautism.co.uk/article?id=222

Willis, J. W. (2007) *Foundations of qualitative research: interpretive and critical approaches*. London: Sage.

Wing, L. & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children Epidemiology and classification. *Journal of Autism and Childhood Schizophrenia*, 9, 11-29.

Wolfensberger, W. (1973) The future of residential services for the mentally retarded. *Journal of Clinical Child Psychology*, no. 2, pp. 19–20.

Wolfensberger, W., Thomas, S. & Caruso, G. (1996). 'Some of the Universal "Good Things of Life" Which the Implementation of Social Role Valorization Can be Expected to Make More Accessible to Devalued People'. *The International Social Role Valorisation Journal*, vol. 2, no. 2, pp. 12-14.

Wolff, S. (2004) The history of autism. *European Child and Adolescent Psychiatry* Journal, vol. 13, pp. 201-208.

Woodbridge, K., and Fulford, K.W.M. (2004) *'Whose Values?' A workbook for values-based practice in mental health care*. London: The Sainsbury Centre for Mental Health.

World Health Organisation (2013) *Autism spectrum disorders & other development disorders: From raising awareness to building capacity*, Geneva: WHO.

Website References:

Autism.org.uk. (2017) *Autism facts and history - NAS*. [online] Available at: http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx [Accessed 15 Apr. 2015].

Care Quality Commission (2012) *Physical Interventions for Challenging Behaviour*. [online] Available at: http://www.cqc.org.uk/ [Accessed 15 Apr. 2015].

Challenging Behaviour Foundation (2012) *Physical Interventions for Challenging Behaviour*. [online] Available at:

http://www.challengingbehaviour.org.uk/learning-disability-files/11_Physical-Interventions-2013.pdf [Accessed 15 Apr. 2015].

Mental Health Foundation. (2017). *Learning disability statistics: autism*. [online] Available at: https://www.mentalhealth.org.uk/learning-disabilities/help-information/statistics/learning-disability-statistics-/187690 [Accessed 15 Apr. 2015].

Silent Minority. (1981). Directed by Nigel Evans for ATV/ITV England. Available at:http://www.bild.org.uk/about-bild/40years/1980s-leading-the-way/ [Accessed 15 Apr. 2015].

United Kingdom Clinical Ethics Network. Ethox approach [Internet]. Flowchart. Coventry: UK Clinical Ethics Network. [Accessed 2015 April 3]. Available from:http://www.ethics-network.org.uk/ homepagecontent/The%20Ethox%20Approach%20Worksheet.pdf

Literature Search Strategy

The development of a search strategy is an iterative process and requires a multi-dimensional approach. The first task was to gather literature to be reviewed; therefore a search strategy was designed in order to maximise the scope of the search.

Search following search databases were used:

- EBSCO
- NIHCE
- PubMed
- Social Care Institute for Clinical Excellence
- Emerald

In additional, searches were made for material originating from UK and international Government websites, the British Institute for Learning Disabilities, National Autistic Society, and Skills for Care & Skills for Health. Internet searches using 'Google' as a search engine was also used and all identified a plethora of journals, articles, blogs, reports and guidance on autism and positive behaviour support.

Search strategy words included: autism, autistic spectrum condition (disorder), positive behaviour support, challenging behaviour, behaviours of concern, complex needs, self harm, self injury, aggression, learning disability, intellectual disability.

Journals that were known to me within my practice were hand searched, and reference lists were checked for relevant citations and led to other journals and papers to be considered.

All the literature identified in searches was screened for its relevance to the study by reading abstracts of each paper. Where abstracts discussed the search words above then it was retrieved in its entirety for further assessment.
Papers included in the final review were read and data extracted using the research framework (Chapter 4: figure 4).

Governance & Ethics

'Development and National Integration of a Positive Behavioural Support Framework for Autism Practitioners', conducted by Lisa Alcorn during the Professional Doctorate programme will follow the University Research Ethics Principles of:

- Research should be designed, reviewed and undertaken according to the highest possible standards. It should comply with University Governance, Professional Codes of Practice and the law.

- Research with human participants must protect their dignity, rights, safety and well-being.

- Participants must be completely informed about the purposes, methods and intended uses of the research. They must be informed about what participation will involve and the risks and benefits fully explained. Any research proposing deviation from this principle may be approved but only in very specific contexts in which the lack of complete information is justified by the benefits of the research.

- Participants must consent to participate in the research having been fully informed about what participation will involve. Participation must be voluntary. The use of incentives to encourage participation is acceptable but these must be appropriate.

- Participants must be allowed to withdraw themselves from participation at any time and for any reason without disadvantage.

- Information and data obtained about participants must be confidential. Anonymity should be maintained wherever possible. All information held about the participants must be processed, retained, stored, and disposed of in accordance with the law.

- The research must protect the dignity, rights, safety and well-being of the research workers who should completely understand the risks and benefits of the research.

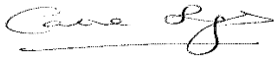
- The research must protect the reputation, safety and well-being of the University of Sunderland. The University should completely understand the risks and benefits of the research.

The following Research Projects have to be reviewed by the University REC according to its guidelines. Please refer to FLOWCHART. This research is that which:

- has children as participants (no exceptions)
- has adults as participants (some exceptions)
- involves the use or storage of human tissues, organs, cells or other bodily materials;
- involves the genetic modification of cells;
- has some other significant ethical risk as judged by Principal Investigator.

I understand that in order to use the process of 'Self-Certification' for any projects, I must have received University Staff Research Ethics Training. Projects that can be Self-Certified are defined as :

Questionnaires, interviews, discussion-groups, surveys, audits, evaluations, workshops or any other discussion or questioning forum that falls under this general definition, provided the participants are fully informed, consenting, healthy adults and the Chief Investigator judges that the research questions have very low ethical & moral risk.

Signed  (Principal Investigator)

Name: DR CATHERINE HAYES

Date: February 25th 2012

RESEARCH INFORMATION SHEET

Study Title: A Holistic Positive Behaviour Support Practice Framework for Autism Practitioners

Inclusion Criteria: The participant (e.g. individual or organisation) who take part in this study must support individuals with an autism specific condition or provide autism specific services in social care and/or education).

Exclusion Criteria: Individuals and/or organisations that do not directly support people with an autism spectrum condition.

Study Aims: The main research is to design and implement a Holistic Positive Behaviour Support Practice Framework for Autism Practitioners nationally in order to provide them with core competencies and capabilities required to support people with autism who may challenge services. The outcome of the study will provide organisations and commissioners of training with an empirical practice framework that improves the outcomes, e.g. quality of life for both service users and staff alike.

The study will also contribute to a Professional Doctorate (DProf) with a secondary intention for this Practice Framework to be accredited by the British Institute for Learning Disabilities (BILD).

What will I actually have to do? The participant will either be involved in attending interviews, focus groups which will be recorded, complete a questionnaire or pen portrait of a service user. The method of participation will be dependent upon the participant's role within the organisation.

Participants will be consulted prior to any appointments being made and also the time involved so that any disruption to participants substantive duties are limited or avoided.

What risks are there? Risks are considered controllable within this study however the researcher will make every effort to identify and pre-empt possible risks and reduce where possible. The participant or the researcher may request a risk assessment be established in order to evaluate the benefits to proceeding against not proceeding. It is the duty of the researcher to protect the health, dignity, and integrity, right to self-determination, privacy, and confidentiality of personal information of research participants. Participants will be provided with the study risk assessment if requested prior to commencement and consent being agreed.

(*The Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects*).

What advantages are there? Using an action research approach supported by organisational a single case study will empower participants to contribute to the development of an innovative training framework that will make a significant contribution to their community of practice.

Expenses and payment: There will be no payment or incentives for the participation of this study. At no time will participants incur a cost to participation.

Confidentiality: The researcher will have access to participants' personal data, which will be anonymised for public dissemination. At no time will personal data be used that can identify an individual or organisation. Nobody apart from the researcher will be permitted to hear your interview or read any transcription of your responses.

In order to strengthen the ethical standards required in this study there may also be a data monitoring or audit of confidentiality procedures by the University of Sunderland to ensure that the researcher is complying with standards and regulations.

All personal data will be stored either as hard copies in a locked cabinet or electronically using password-protected safeguards. This information will only be stored for the duration of the study (approx. 2 years) and then destroyed permanently using either secure shredding systems or wiping permanently from the centrally held computer.

The results of the study will be presented within a thesis report and the participating organisation will be provided with a summary report whilst still preserving anonymity. The organisation may check that anonymity has been assured and the researcher will not submit the final thesis until this has been confirmed. Participants will not be granted any editorial control over the report content.

NOTE: During the course of the study if a participant discloses information of a safeguarding or poor practice nature, which could potentially cause harm to either themselves, others or the organisation's reputation then the researcher is bound both organisationally and through legislation to report this to either the organisation's Designated Safeguarding Officer or to the Local Safeguarding Board. Any evidence will therefore be passed to the Designated Officer.

Code of Practice and Conduct: Both the researcher and the participant are explicitly bound by the organisations policies and procedures set out in social care and education legislation.

Do I have to take part? This study is entirely voluntary and participants will be free to withdraw from the whole study at any time. Participants may also withdraw without giving any reason and without any penalty.

Withdrawal or Refusal: Although participants can physically withdraw themselves from the project at any time, their data may not be able to be withdrawn if the study is

well progressed. All participant data however will be anonymised and therefore cannot be identified and removed.

Where participants are involved in interviews they have the right to refuse to answer any question, and that the interview can be stopped at any time and without giving reason.

Who has approved of the study? This study has been approved by the University of Sunderland Research Ethics Committee. Furthermore the research has also been approved by the organisation in which the participant is employed. The participant may request evidence of this before consenting to this research.

Contact details for further Information: If participants require further information about this study or they feel there is something wrong about the research or how it is conducted they may contact anyone of the named individuals below:

Lisa Alcorn (*Researcher*)
Company address & Contact details here

Tel:
Email:

Or

Chief Executive Officer (*Participating Organisation*)
Company Address

Tel:
Email:

You may also contact:

Dr. E. Drews (*Chairperson of Research Ethics Committee*)
Faculty of Applied Sciences
David Goldman Informatics Centre
University of Sunderland
Sunderland
Tel: 0191 5152624
Email: etta.drews@sunderland.ac.uk

This study has been approved by the University of Sunderland Research Ethics Committee

Ref: Appendix D/LA

Address:

Date:

Dear Sir,

Re: Research study 'A Holistic Positive Behaviour Support Practice Framework for Autism Practitioners – Participant Organisations

I am writing to you in order to request permission to undertake a research study into designing and implementing a Holistic Positive Behaviour Support Practice Framework for Autism Practitioners. To provide some context to my motivation for this study the following literature review provides a summary which I know are the challenges within all organisations who support people with autistic spectrum conditions.

Positive Behaviour Support is increasingly viewed as the preferred service approach for people who challenge, but skills are insufficiently widespread. The need for effective practice standards and training has been highlighted as a key factor in high quality service provision, with investigators recommending a multidimensional approach to increase effectiveness and improve quality of life for service users as well as support staff. We have seen the devastation when this is not in place and more recently in the Winterbourne View case.

Leadership, policy and practice standards are essential in promoting quality and safe practice however specialised training frameworks specific to supporting people with ASC who also challenge is less readily available with no good evidence based research available.

This doctoral study will assist autism specific organisations in evolving their knowledge and practice in order to develop and sustain a skilled and capable workforce. It will also provide systems in performance management to evaluate the organisational strategic and operational performance and evaluate the positive impact at an individual quality of life level.

I have enclosed a copy of the *Research Consent Form*, *Research Information Sheet* for your consideration. If you require any further information about this study please do not hesitate to contact me. I would be grateful if you could complete the enclosed consent form and return this to me.

Yours Sincerely,

Lisa Alcorn

Enc: Research Consent Form
Research Information Sheet

Appendix E

Address:

Date:

Dear Lisa

Re: Research study 'A Holistic Positive Behaviour Support Practice Framework for Autism Practitioners – Participant Organisations

I am writing to confirm that we have discussed your research proposal with our Board of Management and are happy to proceed.

Your proposal sounds very exciting and we are exceptionally lucky to have you undertake this research within our organisation. Supporting people with autism is extremely complex and also very rewarding and if your study can enhance this within our leadership and practitioner team, the lives of the people we support would certainly be enriched.

We look forward to supporting you on this journey.

Yours Sincerely

Name
(Removed for confidentiality)

Appendix F

Ref: Appendix F/LA

Address:

Date:

Dear Participant,

Re: Research study 'A Holistic Positive Behaviour Support Practice Framework for Autism Practitioners – Participants

I am writing to you in order to request permission to undertake a research study into designing and implementing a Holistic Positive Behaviour Support Practice Framework for Autism Practitioners.

Positive Behaviour Support is increasingly viewed as the preferred service approach for people with autism, but skills are insufficiently widespread and often inconsistent with policy and practice.

The need for clinically effective practice standards will not only support people with autism to have a better quality of life but will enhance the clinical skills of practitioners.

This doctoral project will assist autism specific practitioners in developing their knowledge and practice in order to develop and sustain a skilled and capable workforce alongside gaining valued continuous professional skills.

The eligibility criteria is the following:

Leaders: Participants need to be either a Service Director or Service Manager overseeing autism specific services – these participants will take part in 2 semi-structured interviews lasting no longer than 30 minutes.

Autism Practitioners: Participants need to be directly supporting people with autism – these participants will be involved in 2 focus group sessions with a maximum of 12 colleagues. Sessions will last no longer than 2 hours. Participants will also be required to complete a questionnaire.

I have enclosed a copy of the *Research Consent Form, Research Information Sheet* for your consideration. If you require any further information about this study please do not hesitate to contact me. I would be grateful if you could complete the enclosed consent form and return this to me.

Yours Sincerely,

Lisa Alcorn

Enc: Research Consent Form
Research Information Sheet

PARTICIPANT CONSENT FORM

Study Title: A Holistic Positive Behaviour Support Practice Framework for Autism Practitioners

Name of Participant: …….....

Organisation:

Address:……..…….....

.....

.....

Contact Tel: .....

Contact Email: .....

I/My organisation has been provided with the Research Information Sheet regarding the above study and what my/the organisation's participation will involve.

I give consent for myself / organisation to be a participant in this study.

I also give consent for my personal/organisational data to be used by the research worker within the study. I fully understand that this will be anonymised so that no identification can be made to either myself or my organisation.

Date..... Signed……
Participant

This study has been approved by the University of Sunderland Research Ethics Committee

UNIVERSITY OF SUNDERLAND

Alias Name	Julie
Eligibility Criteria	Director C

Semi Structured Interview - Example

Study Title: *A Holistic Positive Behaviour Support Practice Framework for Autism Practitioners*

POLICY CONTEXT (MACRO ANALYSIS):

		1st Interview	2nd Interview
1.	Can you provide me with a current overview of your position and the scope of your role in services?	I am the Service Director covering the Midlands region. I have just recently gained another complex needs service which takes my total to 74 services. Across the entire region we support 44 service users with autism. Most of these service users display a range of challenging behaviours from needing physical intervention to not engaging with people and refuses support.	My patch is still a very complex area and I have recently re-structured to increase the management support to services. I have introduced another Service Manager to work across a patch of 12 autism specific services. I felt that these 12 services needed more priority focus, mainly due to the levels of challenging behaviour and incidents involving physical intervention.
2.	How do you think national policy has shaped the practice of supporting people with autism who present with behaviours of concern?	I have been in social care for many years and I am also a qualified LD Nurse. The role of the LD Nurse in supported living services has really disappeared and where I have these nurses in place they are more managers than nurses. Sometimes these nurses really struggle with the medical versus social model. We seem to have gone full circle with some of the policy drivers, especially when it comes to person centred planning and normalisation. This was huge probably 20 years ago but it became too diluted and lost its way. Normalisation was totally lost however it's more relevant now than it's ever been. Personalisation is now the driving policy but its really saying the same thing. The idea is great but the problem is still the same as it was 20 years ago – finances and infrastructure! We now have less social workers' and care coordinators and less money to play around with and that's only going to get worse. Leaders like us are expected to	On reading Positive & Proactive Care and Positive & Proactive Workforce I can see how these two publications can influence our organisation. I also have some responsibility for our training department and our training programmes need to change drastically to be more contemporary and to cover the Care Certificate. The autism and behaviour training has been developed to take account of the new legislation and is built into the PBS framework. I couldn't see how this all linked before. We have a number of revised policies that take account of the changing direction of social care. The new PBS policy generated a number of other changes in policies. The MCA/DOLS policy needed to link with the PBS policy and our Safeguarding, Whistleblowing and Complaints policies are all cross functionally related under the PBS approach. The other policy that has changed a

		ensure quality isn't affected and continue to deliver good services with less staff and with less specialist support services. I was hoping that the Autism Act would influence how services were commissioned and delivered however I can't see much change in practice. We are still see services for fit for purpose. The autism leads in local authorities are an interesting mix of people. I have met some outstanding Leads who have a fantastic understanding of the condition, yet I have equally met some that I wonder how they got the job. It's a bit of a postcode lottery as a result. Winterbourne really shocked social care but I wasn't surprised. The Bubb report only magnified the state of social and health care and only told us what we already knew about commissioning process and what areas of transformation were required. We saw the same in the Mansell report and the Sutton and Merton investigation report. The Care Act is now meant to combine everything together, better integration, joined up needs assessments and funding. We are probably working more insular now than we ever have been.	great deal is our restrictive physical intervention policy. It has a more antecedent focus now. I think our principles have shifted somewhat but are much more enhanced because of the framework. We discussed our principles towards people who challenge at the strategic away day. Although we all had come commonality, we equally had some different perceptions and ideologies especially in autism services. As leaders if we couldn't agree we couldn't expect our staff to follow a consistent path. Revising all of the policies has helped to shape our thinking and also our future direction and practice. Now our challenge is to show our commissioners that we can support people with autism positively and safely.
3.	What is your current philosophy/principles of supporting people with autism who present with behaviours of concern?	I think we have very sound principles of practice in our organisation. It's the first thing you see when you look at our website and it's the first thing you hear at induction. A Director is always at the first day of induction to discuss these principles. I think that sends out a really strong message to our staff that we are committed to these principles within our practice. We want to empower our service users in which way they are capable. We don't focus on their disability but we look at what they are good at, interested in and motivated by.	The PBS framework has only enhanced what we already have and is now evidencing these principles in the reality of what we are doing. That's something we have often struggled with. I like that fact that it is teaching our staff to think about the messages of the behaviour rather than the behaviour itself. It's about looking at the quality of a person's life and enhancing this as much as possible so that the service user doesn't have a need to display behaviour.

		We are a very compassionate organisation, which is only right considering we are supporting the countries most vulnerable people. I talk to my teams a lot about balancing risk with choice and freedom more so because they don't get MCA/DOLS and how, if we don't get this right can lead to a deprivation. We embed these principles into our supervision and support structure; and our Social Care Governance commitment charter influences our practice.	The value of systems change within environments has been a huge success in my services. Its given services the incentive they have needed to change structures and procedures but more importantly why this needed to be changed.

LEADERSHIP CONTEXT (MACRO ANALYSIS):

4.	Focusing on leadership and governance within your organisation, how have you approached this in both policy and practice?	As an organisation we have not seen this as a priority and I do think it has caused us to have a number of quality and performance issues. Not just in my area but across the whole organisation. I have tried to use working groups to generate discussions on certain policies, for example the MCA/DOLS policy however time is critical and extremely precious so it often means we start with a good turn out and then over time it dwindles due to managers having to prioritise the service. I do ensure that my managers come together at least monthly for a few hours so that I can update them on developments so this is often where the policies and practice issues sit. We also review incidents at this meeting to make sure that everything possible has been completed. I also have my PA who is sort of a like a triage person who collates all incidents and informs me of any that require closer and more urgent attention. I get so many that it would take me days to get through them individually.	Governance is really the thread throughout the PBS framework and it's great that we now have a Board PBS Lead with meets with the PBS team regularly. The progress reports are accessible to all our staff and not just the leaders and managers. That's a really good way of supporting and communicating with our workforce so that they are fully involved. I attended a periodic service review last week and it as interesting to see the improvements in reductions of his behaviour. It was a good opportunity to see how this protects the planning structure, rights and process. I think we could learn a lot from this approach in other areas of our work. I wouldn't mind using the periodic review for all of the support planning arrangements because it's certainly transferrable. I am now in a position to govern the framework myself because I have undertaken some of the training. I think this is paramount for the governance arrangements and also to be able to lead and endorse the framework. The new PBS policy has been a

		My managers are very good and actions and follows ups that are needed following incidents. We are not so strong on de-briefs though and we could really do with some training in this area. All incidents are collated at Head Office by the H&S team and their job is to go through these incidents thoroughly. It's good to have an objective overview and to also ensure that our practice is consistent with our policies and procedures. This all goes forward to the Social Care Governance Group which offers an appraisal of the statistical and performance indicators of the organisation. I normally take this back to my managers so that we can discuss and identify our areas of concern. An action plan is then drawn up so that we can evidence how we are monitoring and managing the service.	welcome and long overdue policy in our organisation. It's been wrote in a useable way and I can see the practitioner flavour throughout the policy which our staff really like because it makes sense to them. That's the strength the policy has and governance becomes more robust.
5.	How have you disseminated knowledge to managers who oversee autism services on a day-to-day basis to ensure policies are met?	Our dissemination procedures are fairly traditional and haven't changed for many years. We are far too reliant on paper systems and our intranet system isn't used to its full capacity. That's because we have a lot of staff who don't know how to use computers. We have put workshops and IT lessons for these staff but it's not working. We therefore rely a lot on face to face meetings which I am certainly not saying we should get rid of but this can be very time consuming and when you have a large patch to work across this is a real challenge. All policies and procedures are discussed in our managers meetings and then disseminated by the managers. This way I can talk managers through the policies fist. It's really important that managers understand these policies because they are communicating this to their teams.	After talking to you about how to disseminate the PBS and autism policies I can now see how the PBS framework can be utilised flexibly. The PBS referral system is a great way of responding to the services' needs and we used this to disseminate the policies. This was great because it was a practitioner who communicates the message of the policies to the staff. At the same meeting the practitioner helped to facilitate a discussion about how the policy would apply to the service users and staff in our services. This was a fantastic way to avoid any misunderstandings. At least if we have any further concerns we can refer again. I like the way the autism policies feed into the PBS framework so that staff can understand how autism and can affect a person's behaviour. I do think the autism often gets lost when behaviour is present and staff don't

		The autism policies are a good example, which I am still a bit concerned about. Some of my managers have not had any autism training for a long time however the new policies are very comprehensive. I am not sure how competent the managers are to be able to interpret these and communicate this effectively.	pick this up.
6.	Do you think leaders hold enough knowledge of PBS? If not, why is this and what knowledge to you think is needed?	Well I certainly don't know enough about it and I think I keep myself up to date with changes in legislation and practice due to being a nurse. I have heard about this approach but never been in a position to understand it thoroughly because I normally get caught up with other things on the day. I know that the government launched a document last year about the PBS model and that after Winterbourne this was considered the new innovative practice but I don't know enough about the way it is practiced. I know in my services we are challenged by behaviour because we don't understand the reasons why it is happening. Person centred understanding helps to some extent but after that we are left scratching our heads and at times referring to specialist outside of the organisation. I don't think we get the planning and strategies right at times either and are often wrote poorly or left up to interpretation which can cause no end of problems.	We are certainly more informed now than ever. Your presentation at the Board meeting really gave a good overview of what our responsibilities as leaders are. I also thought how this filtered into Leadership workshops with senior managers and project managers were a good way for everyone to understand their roles and responsibilities. The governance arrangements will ensure these are met. Leaders (including myself) didn't know the full extent of our responsibilities under PBS and I think because we had strategic leads in this area and autism, it has really been left to you but I think that is changing now. There were quite a few things that I didn't know before. Some examples of this are: ▪ Having a Board lead for corporate responsibility; ▪ Risk register for physical interventions; ▪ To be true to PBS plans must have a functional behaviour assessment that is baselined and measured; These are crucial to ensure PBS is successful.

COMMUNITY OF PRACTICE CONTEXT (MESO ANALYSIS):

7.	Can you tell me about some of the experiences you have had in leading services that support	We have a very complex service in a rural area which is a challenge because of the location just as much as the complexities	We've been able to resolve some of these issues now. The environmental and sensory assessments were very useful in understanding how to

	people with autism? What were your challenges?	in people's autism and behaviours. The service was specially designed and built for people with autism and complex neds but thinking about it now the layout is actually part of the problem for some of the service users. It's all well and good building and designing a home for people with autism but what hadn't really been considered was the changing needs of these people. We have to try and keep people separated which is a difficult thing to do when service users live in close confinement to one another. It's also not consistent with a supported living philosophy and life should not be about keeping people separated. We have discussed this with commissioners who have empathised with the problem but haven't come up with any solutions because accommodation wise, there isn't anything else on offer. We have received a few more hours here And there for some service users but this is too reactive and not solving the problems. In fact more staff in the home actually creates more behaviours. People can't be expected to manage their behaviours all of the time by getting them out of the building. What if they want to stay in for the day as some of our people do. We often have cycles of behaviours from some of our service users and these can be very challenging because the service user will present with aggressive behaviour towards each other or to staff. We have even had the property damaged on several occasions. Staff get very tired and that's when we see difficulties within	structure and manage the environments for our service users. It's never going to be ideal with this building but at least we feel it has improved. Just by changing colour schemes, lighting, layout and staff support times has reduced some of the environmental risk factors. These might sound like they are common sense but when you throw autism and behaviour into the mix you can lose sight of these things. More importantly though, we are more informed about why this needs doing. We now have a dedicated PBS Practitioner who visits our service every 2 weeks to review incidents and the PBS plans. This is a good opportunity for staff to ask her question and also clarify. This way our PBS Practitioner understands the person's needs much better and reassures the staff. Staff have commented that they feel much more confident and can see how this is going to help in the future when the difficult cycles start.

		the team. We have tried to bank some hours to use at these times but the problem we have is that we don't have surplus staff that can be utilised. Our behaviour colleagues are often called but they don't have an in-depth understanding of these service users so we have to start these discussions all over again. We also tend to see a different specialist on each occasion which doesn't give us any continuity.	
8.	Have you ever experienced a 'toxic' environment and if so, what were the toxic components?	Lots of times especially those that transfer to us such as TUPE transfers. Changing practices especially in supporting service users to take positive risks as staff tend to be very risk averse but unfortunately often infringes the rights of our service users. MCA/DOLS is a classic example of this. Staff are often extremely resistant to these types of changes which causes lots of management problems. It does become a bit like battle of the wills between management and staff. We also have challenges with the type of accommodation some of our people live in. I have experienced lots of transition challenges when young people transfer into adult services. Looked after children live in some beautiful homes that are very spacious and well-staffed. It's a bit of a shock once they hit adult services! A prime example of this is we have a young man you previously had his own large apartment in children's services. He then transfers to us and still has an apartment but it's a postage stamp compared to what he had before. We have seen a massive decline in his behaviour and mood. A lot of staff has also moved on so some of this historical understanding has been	Having thought about this question after our last interview I would now think that at least 20-30% of my services have a toxic mix in them. The majority I would say are due to the type of environment, which to a large extent is out of our control although we do try and ensure this is risk assessed and reduced where possible. There are also compatibility challenges and their changing needs that have increased the risks towards each other. We have some great staff members but some can also magnify these challenges even further. This can have a real ripple effect throughout the teams and trying to change mind-sets is one of the day-to-day challenges for my managers. I would say that a lot of the managers job is taken up with trying to sort out staff issues rather than service user issues. We have also had a number of issues with a few staff (certainly not all) who don't see the value in the PBS plan. I think this has really challenged the manager who believes whole-heartedly in the model and cannot understand why a person would resist an ethical and person centred plan. I have had to spend some time with this manager talking him through how to address this. It is probably going to end up down a performance route with these staff, as their values are obviously not in line with ours but more importantly the service users.

		lost. If wasn't until a staff member started that they commented on this and said that it will have played a big part in how he is now feeling. We have had to fight to get him re-assessed but the challenge now is to find somewhere suitable for him. This will cost because he needs his own place but the commissioners are still trying to get him placed in a shared service.	
9.	How did you address this toxic environment?	Through a lot of pestering the social worker and lots of persistent meetings in a nutshell. It's really not the social workers fault as they are trying their best just like we are but they too have limited resources and financial pressures placed on them. We asked for a full assessment but that took some time but at least the staff felt like something was happening for him. This also reassured his father.	The new PBS plans are great to capture the patterns of behaviour and the PSR shows all of the historical behaviour information. I wished we had this when he moved in because we may have been able to evidence and show measurements of a decline in wellbeing much sooner. I think the de-briefing system is another practice that he helped reduce a toxic environment. It's a constructive way for colleagues to challenge their practices in a controlled way. These are used every time there has been an incident so that staff can reflect on the areas of practice and against the PBS plan.
10.	How do you think a set of practice standards in PBS that addresses policy into practice would benefit the community?	There is a lot of information out there and there is a danger that we have information overload. I'm all for making the job easier so if these practice standards can bring all of this information together in some way then that would be great.	After learning about the standards myself I can certainly see the value and absolute necessity of them. They do actually bring all of the information that's out there into a condensed set of standards. It's much easier to look at these standards than through the several documents that we are expected to use in practice. It certainly helps me to understand what I am expected to know but more importantly do. The assessment and planning section has been great for us as it has contributed to some of our service users getting the right levels of support. It hasn't always been about getting more support; it's also about recognising people's abilities and managing proactively the risks. That should be music to commissioners as there is money saving for them.

			The de-briefing and the central database are areas of performance that we had not been so strong on. I had never even thought about baseline behaviour measurements before and especially not in measuring these before the start of the PBS plan. Its so obvious really but sometimes we are blind when it comes to simple things.

Appendix I

UNIVERSITY OF SUNDERLAND

Focus Group - Example

Focus Group	A
Region	North East

Study Title: *A Holistic Positive Behaviour Support Practice Framework for Autism Practitioners*

(MACRO ANALYSIS):

		1st Focus Group	2nd Focus Group
1.	***Policy dissemination***: How is the PBS policy communicated to the workforce?	Not really sure that it actually is communicated to the workforce. We have a system known as Citrix where all of our service information is, including the policies. Normally we all get an email from Citrix saying that there has been a policy update. What is then meant to happen is our manager discusses the policy in our team meetings. Sometimes though we might not have a team meeting for months. It's normally because we are short staffed so we can go months without even looking at any policies. There's really not enough time to read them.	There has been a lot of changes with regards to the policy and how this is communicated to the staff team: ▪ Focus groups with the staff to discuss the policy and their experiences. Even the service users were involved in some ways. ▪ The Director facilitated the focus groups. ▪ Principles of PBS were really good to discuss and who were the PBS team members. ▪ Staff commented how positive the session was and how involved they were.
2.	***Leadership & Management:*** How much discussion and interaction do you have with leaders and managers about supporting people who challenge?	Our manager is really approachable and we discuss things like a service users behaviour on a daily basis. This really helps to make sure that we are all doing the same things when supporting the person. Our Director is very much hands on and regularly visits our services. She is very approachable and asks us how things are going. We can have some really honest discussions about behaviour with our Director and Manager but they too will often say they are at a loss with what to do sometimes. She will help us by sourcing the right professionals to come in and talk or train us. This can make all of the difference.	▪ We know who the lead person is now and we can go to them if we have any concerns or want to raise an issue about the policy or how it is being practiced. ▪ PBS Lead has visited our services and sat in on meetings to hear our experiences. ▪ Managers have received training on the PBS framework and fed this back to staff. Our manager is really positive about PBS.

3.	***Organisational Constraints*:** What would you consider the constraints in supporting people in your services at the moment?	Some of the service users that we support are not really compatible with each other. This makes it really difficult to prevent behaviours, especially when they live in small homes in the community. We don't really get a say on who lives with who and don't really understand how this is assessed. It just seems that we hear about a referral and then the next minute they are moving in. Most of the time we don't get to read any information on the person until they move in which causes the service user to become anxious. We often feel that service users should have more staff than what they are allocated. We often have to pull from other support packages to help with a service user who is very aggressive. We never have enough staff. Staff often get hurt because of this. We just keep getting told that this is all that commissioners will pay. We never really get a break either which means we are tired and have to work long hours because we are short staffed.	▪ The environment is always going to be a problem but we have been shown ways of adapting environments to meet the needs of the service users through assessments. This has reduced the incidents between service users. ▪ Active Support implemented so service users are busier and this has not cost extra money. ▪ Sickness has improved, as people feel more supported. ▪ Compatibility is less of a problem now because service users are engaged in meaningful activities and they are constructively spending positive time with each other. ▪ We have had no referrals as we have maintained the service users placements who currently live here.

(MACRO ANALYSIS):

4.	***Values & Attitudes***: In what ways do values and attitudes affect staff and teams clinical practice when supporting people who challenge?	When staff are in positive moods this tends to rub off on the service users. The service users can really pick up on the moods of staff when they are feeling down, tired or negative. There are times when we do get disheartened especially when it comes to person centred approaches. Due to the way the funding is working people really don't have true person centred support. An example of this is a service user who only gets 15 hours of 1:1 support. Often we can't give him the time because he's had his support and we have to support other service users. This gets him really upset and he often punches the wall. Staff end	▪ Understanding how staff can cause a toxic environment with their attitudes has been of great help as not only the manager challenges this, so do the team, which keeps the culture and practices healthy. ▪ We are more creative as a team and when we can't do something because of say, funding, we consider other ways of doing this. ▪ Staff are very motivated and we have set

		up giving him the time because we don't want to see him like this. The service doesn't get paid for this and its just more pressure on the staff. Staff do become de-motivated and undervalued because the pressure in more but the pay isn't. We try not to let this show but there are some staff that don't even bother hiding this. We are expected to know so much about our service user but we aren't given the time to read plan let alone digest it. We do have a great team though and it's a team that has seen little turnover because we are so close and love our service users.	performance targets to help the service user achieve. This keeps us on track and focused. We are really on board with PBS. ▪ We spend loads of time talking, thinking and reflecting about our practices.
5.	***Organisation Context***: How do you currently support a person who is presenting with behaviours of concern and what are your biggest challenges?	We try and give the service user space but that's really hard in a small home when other people with autism live there. It causes like a domino effect. We know our service users really well so we can spot the early signs and try and divert them. We try and figure out what the problem is but sometimes there is no trigger. Everyone tries to help but often there is only a couple of us because we are short staffed. One tends to take the lead whilst the other supports the other service users. We alternate if the service user is focused on us. We will normally try what we know the person user likes and start with that. Sometimes we just don't know what is wrong and we just have to see the behaviour through. We often feel helpless. We don't think we understand autism as much as we should so we are left to figure the behaviours out ourselves. We often talk about this as it's a huge problem.	We do this so differently now and consider so many other factors: ▪ Each service user has an active activity planner which means service users don't spend a great deal of time together if they are affected by each others behaviours. ▪ Lots of exercise and wellbeing activities have been introduced. We even created a space for exercise. ▪ Understanding how to communicate effectively e.g. understand processing time of a person with autism, knowing the right methods of communication, at what level etc. This has had a massive improvement on behaviours. ▪ Adapting the environment when we spot the early wellbeing signs of stress, e.g. just adapting lights can help! ▪ Giving service users space and time to process what's

			happening next and giving them some visual cues has reduced incidents during transition. Understanding autism and transition has especially improved this massively.
6.	***Training/Resource Allocation***: What training resources do you currently receive and what do you think you require to improve your knowledge and skills?	We do lots of training from mandatory to more specialised such as autism training but it never really hits the spot. Its great sitting in a classroom learning about autism but it seems so different when you see it through our own eyes. We also do training on challenging behaviour, which is really good and we have to refresh this every couple of years along with PI training. We really could do with some training on incident recording. We constantly get pulled up for this not being right but nobody has trained us so that's to be expected.	The training that we have had since the PBS framework was introduced has been great as it has all been related to the needs of the service users. This has helped us understand our service users much more in depth. How autism affects one person can be totally different to another so the generalised training we have had in the past hasn't really done the job for us. We would like more training that is person centred as we have got so much out of what we have already taken part in. Our incident reports have also improved since the last session, which CQC commented on during an inspection last week.

(MICRO ANALYSIS):

7.	***PBS Assessment & Planning***: How involved are staff in the assessment, design and implementation of PBS plans?	Very little as the manager tends to write these. Our manager will at times ask us questions about the service users behaviours but normally we are given the plan to read once its completed. We can ask for other things to go in or be changed though. The assessment is normally done before the service user moves in but we've never seen any of that information.	We are involved from start to finish of the assessment procedure. When a referral comes in we all get to read the initial referral and the manager and staff then consider an appropriate key worker to go out with the manager to do the assessment. We can all read the information after their visits. The manager then talks us through the completed assessment and we even get to have a say in if the placement is appropriate. We are learning how to write PBS plans which is very interesting. At the end of the day we are involved now which is a big step forward. Time will tell

			how beneficial this will be. The morale has certainly improved as staff feel listened too and involved.
8.	***Clinical Practice***: Do practitioners understand why and how to implement the strategies from the PBS plan?	No, not at all. We are often left with wondering why something happened. It's like there are loose ends all of the time. The more we get to know the service user the better as we can understand some things but there are loads of times when we didn't know why things happened. Sometimes the PBS plans doesn't work and even professionals don't know what to do so we are left to get on with it. It's really not fair to the service user or the staff. We had a service user who was very challenging and it went on for months and people got hurt. The team was totally stressed out. Professionals said it was just his autism but we knew it was mental health but they didn't listen to us until he ended up becoming violent one day and seriously hurting another service user. Then the professionals acted and agreed it was his mental health. We had to fight and fight to get him the right treatment but that affected everyone and not just him.	We certainly have a better understanding, which is improving daily. We look at the behaviour differently now and focus more on the person. We are considering the person's autism much more and how this impacts on them and look at ways of reducing the stress levels. The PBS plans are wrote in a much better way and follow a gradient approach to intervention. This helps us to make sure we are mindful of rights and restrictions. They explain how to do a strategy much better, which reduces the problems with inconsistencies.
9.	***Recording & Monitoring***: How do your records help you to improve your clinical practice of PBS and respond better to the person with autism?	They should help us to understand the service users behaviours better and look at other ways of supporting them but this doesn't happen. We really don't get the time to sit as a team and discuss incidents. We are lucky if we get a de-brief and then sometimes that's not enough.	▪ We all monitor incidents now and the policy makes it clear on who has what responsibilities. ▪ Incident record has changed to ensure it provides us with the right information to learn. ▪ Sections include what worked and what didn't and we can reflect on this. ▪ Actions by management have to be within 24 hours so our responses are getting better. Managers and Directors have to respond to the incident report and feedback to staff.

10.	***Practice Standards***: If you had practice standards for supporting people with autism who may also challenge, how do you think this would affect your own (and teams) practice?	We would have a better understanding of what we needed to do. Often we are just left in the dark trying the best we can do to stop behaviours. Just knowing there is a system there to help is reassurance in itself. We really want to learn more about service users behaviours but the training it just not enough.	▪ More reflective in practice ▪ More creative in our strategies ▪ More knowledgeable of autism and PBS ▪ Confident in all areas. ▪ Better incident recordings. ▪ Morale is high ▪ Less staff stress and overall feel supported. ▪ Understand the legal parts better. ▪ Improvements recognised by CQC and social workers. ▪ Reduced incidents in behaviour.

UNIVERSITY OF SUNDERLAND

Professional Doctorate

Interview Protocol Checklist

Study Title: *A Holistic Positive Behaviour Support Practice Framework for Autism Practitioners*

Alias Name	
Eligibility Criteria	

Prior to Interview:

No.	Protocol Description	Completed YES/NO
1	Eligibility criteria for participant is congruent with sampling methodology	
2	Write to participant outlining the research project and enclose research information sheet, consent form and research risk assessment	
3	Meet or discuss with participant if requested	
4	Consent form signed and returned to researcher	
5	Visit research location where possible and meet participant and check interview location – assess if research risk assessment needs amending or H&S considered	
6	Arrange pre-interview and post interview dates and times	
7	Send semi structured interview questions ahead of interview with covering letter	
8	Request an email confirming the interview will go ahead 48 hours prior to face to face meeting	
9	Check Dictaphone is working, spare batteries and tapes etc. Ensure researcher is equipped with pen and paper for possible note taking	
10	Check interview location prior to commencement: fresh drinking water available and ergonomics of the room checked to ensure relaxed atmosphere	
11	Door sign (if possible) for no interruptions	

During the Interview:

No.	Protocol Description	Completed YES/NO
12	Thank participant for agreeing to be interviewed	
13	Check participant fully understands consent arrangements and research information. Clarify any points that the participant may have	
14	Provide participant with an identification number and alias	
15	Inform participant that a transcript will be provided to check accuracy	
16	Inform that the interview will last no more than 30 minutes	
17	Turn Dictaphone on and provide identification number and alias. Should also include date and time	
18	Conduct the interview	
19	Indicate to the participant that there is only one question left to demonstrate that the interview is coming to a close	
20	Ask the participant if they wish to add further comments	

21	Provide a time frame for sending the transcript to the participant for approving	
22	Check with the participant that they were satisfied in how the interview was conducted	

After the Interview:

No.	Protocol Description	Completed YES/NO
23	Researcher to privately record their own observations for reflective log portfolio and for analysable data	
24	Transcribe interview verbatim	
25	Use indexing on transcript	
26	Return a copy of the transcript to the participant to check for accuracy	
27	Participant to confirm accuracy via email where possible	
28	Store transcript confidentially	

UNIVERSITY OF SUNDERLAND

Professional Doctorate

Focus Group Protocol Checklist

Study Title: *A Holistic Positive Behaviour Support Practice Framework for Autism Practitioners*

Focus Group	A / B / C / D

Prior to Focus group:

No.	Protocol Description	Completed YES/NO
1	Ensure participants receive Research Information Sheet outlining the aims and objectives of the study.	
2	Ensure consent forms have also been sent.	
3	Ensure all participants also receive Focus Group Protocol checklist.	
4	Receive signed consent forms prior to focus group.	
5	Provide participants with the date, time and location of focus group session.	
6	Check environment is a suitable venue e.g. ergonomics, room size, personal space etc.	
7	Structure of the focus group including discussion themes have been planned out over the 2 hour session.	

During the Focus Group:

No.	Protocol Description	Completed YES/NO
8	Ensure room layout is correct and refreshments are available.	
9	Ensure there is a clock directly in front so that time can be checked without distracting participants.	
10	Place a sign on the door shortly prior to commencing the focus group and check all participants are present.	
11	Thank participant for agreeing to the focus group session.	
12	Check participant fully understands consent arrangements and research information. Clarify any points that the participant may have.	
13	Provide participants with an agenda of the session.	
14	Inform participant that a transcript will be provided to check accuracy.	
15	Turn Dictaphone on and provide identification reference code. Should also include date and time.	
16	Conduct the focus group according to the semi-structured agenda.	
17	Ensure all participants have been involved in the discussion, encourage those who are quieter to take part.	
18	Seek clarification where there are contrasting views and probe more to complete research questions.	
19	Identify any non-verbal communication points that may need interpreting. Make a short note about this but do not allow this to distract from the discussion.	
20	45 minutes before the close of the focus group provide participants with the questionnaire.	
21	Indicate to the participant that there is only 10 minutes to go and encourage participants to discuss any areas that they feel are pertinent to the session.	

22	Check with the participant that they were satisfied in how the focus group was conducted.	
23	Thank participants for taking part in the session.	

After the Focus Group:

No.	Protocol Description	Completed YES/NO
24	Immediately after the focus group, write up reflections of the session including the non verbal communication. Link to action – reflection cycle.	
25	Transcribe focus group within 48 hours.	
26	Use indexing on transcript and analyse themes/trends. Do any themes/trends deserve more attention?	
27	Consider context and tone. Are comments phrased negatively or triggered an emotional response, this should be noted in the analysis.	
28	Interpret the results: what are the major findings; does this inform the PBS framework; what are the gaps; does this add to knowledge? Etc.	
29	Complete analysis template to refer back to for the purpose of the report.	

Pen Portrait

Name	William	**Diagnosis**	Autism / Severe Learning Disability
Age	42	**No. of Autism Practitioners**	13

Pen Portrait:

William had previously spent 28 years in an NHS hospital provision prior to moving into this supported living tenancy. His staff team transferred with him 6 years ago. William lives with one other tenant who also lived alongside him in the hospital. His home is a two-bedroom bungalow with a large spacious enclosed garden (although never went in it) in a quiet close nit community. William has 1:1 support in the home and 2:1 support in the community. He has no living relatives and is generally fit and healthy.

How autism impacts on the person's quality of life:

William has a high level of anxiety on a daily basis and is constantly challenged by his environment. William can become very distressed when objects are not in the place that he originally put them and will often need to check for reassurance. This checking can often take place at times when he is in the middle of doing something else or he will interrupt his peer's activity in order to check. William is unable to plan his day and struggles when staffing is changed. He requires practitioners who are confident and assertive. If practitioners do not have these skills, William can become very stressed and often results in self-harm and aggression towards his support staff and damage to the environment.

Current behaviour presentation:

William's anxiety levels have reached a point that he is becoming difficult to manage. On an hourly basis in will become focused on certain objects e.g. cups and will want to place them in a certain order. This has led him to want to do this with most objects in the home. It is difficult to manage when he is presenting with this behaviour especially when ordering his peers possessions. When prevented he is physically assaulting staff. This has led to a number of incidents and William is increasingly not leaving the home because of this behaviour. Due to the severity of his behaviour, there has been a significant increase in the use of 'As Required' emergency medication. As an example: May 2014 = 4 administrations to May 2015 = 23 administrations. William's activities have reduced and he will often rush these in order to go check his home.

Challenge(s) within the Service:

The staff team have raised concerns with the severity in William's behaviour and some of the team have requested not to support him due to being assaulted. A number of the team have been very vocal about increasing his medication in order to prevent these incidents occurring and also feel that his behaviour is having a negative impact on the other tenant. The team regularly highlight William's behaviour when he lived at the hospital and have continued to work in the same way for many years. There is some sickness in the team that is related to William's behaviour.

Implementing the PBS Holistic Practice framework:

A PBS referral was made to the PBS Lead Practitioner who organised visiting the service and meeting William and his support staff. During the initial visit staff were very keen to inform the PBS Practitioner about William's behaviours and what they think should happen, e.g. increase medication or look for alternative accommodation. The PBS Practitioner informed the team of the following procedure:

- General health check to rule out any underlying health problems;
- Analysis and evaluation of behaviour baseline;
- Naturalistic Observations of William and of the support he receives;
- Functional behaviour assessment e.g. is the unmet need Sensory, Attention, Escape or Tangible;
- Autism/Sensory Processing assessment;
- Person centred workshop with the team;
- Design of the PBS plan;
- Person centred workshop to disseminate plan;
- Periodic review of the plan to measure baseline

Some members of the team felt this would not make a difference to William and these approaches had been used when he lived at the hospital. Some staff also commented that they knew William very well and would not benefit from the person centred workshops. It was explained to staff that William's behaviour presentation has a different context due to the environment being different. Understanding William's autism and sensory processing in particular would help identify the relevant strategies to support his unmet needs, which are displayed as a behaviour.

Findings of implementing the PBS Holistic framework:

There were a number of outcomes that informed practice and provided staff with new knowledge:

- No underlying health concerns were identified.
- Function on William's behaviour fluctuated between Sensory and Tangible;
- Baseline behaviour was averaging: Monthly frequency: 15 incidents; Monthly duration: 12 minutes; Monthly severity: High; As Required: 24 administrations.
- Limited visual understanding of his day and team relied on verbal communication.
- Autism & Sensory assessments provided a lot of new information:
  - Weak Central Coherence (weak control impulse and perseverance). This had appeared to staff to be OCD however was firmly embedded in this autistic domain;
  - Systemizing – as a result of the above difficulty William was displaying systemizing behaviour which in his way was trying to control the anxiety, e.g. lining up cups, placing tea towels in a certain order and position, opening a certain window, placing bath mat behind door and not in bath. It was highly likely that this environmental context had something similar when he moved into the home and William is reverting back to a familiar context.

PBS Strategies Implemented:

- Structured planning built into William's day to be able to check the environment and position it the way he needs.
- Place a visual reference on other tenants bedroom door explaining no access for William.
- Visual planner, NOW and NEXT board used to inform William of what is happening to help reduce his anxiety levels.
- Sensory integration embedded into his day, e.g. lots of short sensory activities that William could chose. These also needed to be portable so that this strategy could be generalised and transfer in any environment.
- Increased William's physical activity e.g. William likes going to the café so staff would park the vehicle further away to promote exercise whilst still having the motivation of the café.

- Person centred workshop with the team regarding William's autism and sensory needs in order to help understanding of why this is presented as behaviour. Involved the team in developing functionally appropriate proactive strategies for PBS plan.
- Protocol revised for As Required medication administration in reactive section of the PBS plan.

Outcome(s) to increase quality of life:

The following outcomes were achieved by the 6 weeks stage:

- 75% reduction in the use of As Required medication.
- Sensory strategies evident in diverting William's anxieties from systemizing, e.g. staff carry bubbles tube in the home and sensory bag in the community.
- The structured planning first thing in the morning has resulted in William wanting to go out once he has checked the home.
- William has not entered his peer's bedroom.
- William went into his garden for the first time. Staff started to blow bubbles in the garden and William followed the bubbles. He now goes and sits in the garden regularly.
- Staff have noticed William is sleeping better and feel this is because he is able to check the environment before bedtime.
- Behaviour baseline over the past month: Frequency: 4; Duration: 10 minutes; Severity: Medium. Staff also reported that William has not physically assaulted staff although continues to self-injure but the severity of this has also reduced.
- Staff are focusing more on William's autism rather than the behaviour and as a result are being more proactive and pre-empting problems.
- Full complement of staff team in place.
- Staff are gaining in positively and are showing more creative ways of working. Evidence in the last person centred workshop demonstrated that staff are challenging each other's practice and encouraging their colleagues to focus on the current environment rather than what they used to do in the hospital.

Is there evidence of sustaining/improving quality of life? Post response:

- As Required medication administration has reduced further is usage to 83% and this remains constant.
- Frequency remains constant however the average duration is reduced to 6 minutes with a severity rating of low.
- Damage to the environment has stopped completely although self-injury is still evident albeit of low severity.
- William has now been transferred to the Local Authority Review Team due to currently not requiring close attention.
- William continues to use the garden and is initiating this himself rather than following staff.
- Team have reflected on their own practice, values and attitudes and have come to realise this had affected William and them as a team.
- All staff now support William.

Pen Portrait

Name	Rose	**Diagnosis**	Autism / Severe Learning Disability
Age	21	**No. of Autism Practitioners**	35

Pen Portrait:

Rose has recently finished her schooling and moved into her own supported living flat. Rose has her own tenancy and her neighbours are all people with autism and/or learning disabilities. Rose's parents are very active in her life as is her sister who visit Rose every weekend. Rose is a very curious young lady and has a lot of potential to develop her independence much further. Rose has lived at the service since April 2015 so is still settling into her new home and routines. Rose has 2:1 staffing at all times and during incidents can require up to 5 staff.

How autism impacts on the person's quality of life:

Rose's autism is one of the most complex forms of autism. There are so many facets to understanding Rose and how autism impacts on her life. To summarise these:

- A familiar core team of staff are required. Any new people to her team will result in assaults towards them and others.
- Rose needs order in her life and predictable events. Any changes no matter how subtle often causes Rose great distress.
- Rose has difficulty with expressing herself and often goes unnoticed until she displays behaviour. As an example Rose does not like peas however one pea was found in her mashed potato. This resulted in Rose throwing her food and assaulting staff.
- Rose has difficulty separating what she watches on TV with events in her own life. As an example she watches Super Nanny. Not because she enjoys this but to stimulate herself to assault staff.
- Rose expects things literally so if staff provide her with an expected time for a visitor, for example, Rose will put a time to this. If visitors do not arrive at their expected time Rose becomes very distressed which can then affect her entire day.
- Another example: Rose loves to shop in Tesco so staff took her to Tesco not realising this was the 'wrong' Tesco. Rose became very distressed and assaulted staff. This demonstrates that Rose is unable to transfer her skills to an alternative Tesco and was therefore unable to problem solve and express this via verbal communication until after she had calmed down.

Current behaviour presentation:

Rose's baselines are not known at this time due to her only recently transferring to the service however we do know that in the past 5 months there have been 7 restrictive physical interventions (due to physical assaults) and 23 interventions that practitioners have been able to manage environmentally rather than physically. Rose is not prescribed 'As Required' medication. Rose's current behaviours include:

- Biting, hitting, scratching, nipping, pulling hair
- Pulling people to the floor
- Punching windows, slamming doors and throwing objects
- Rose will run at staff and persist with this, which can result in a restrictive physical intervention if staff are unable to move away safely.
- Rose can also manipulate situations so that she can assault staff, e.g. place her IPad on record, set it up in the corner of a room and then assault staff. She will then replay this to watch.
- Rose has recently been assaulting staff whilst in her car.

Challenge(s) within the Service:

This is a service that specialises in autism spectrum conditions and has a track record of supporting very challenging and complex people who still remain in the community today and living positive and active lives. Rose's autism however appears much more complex and there has been suspicions that Pathological Demand Avoidance is also present. Staff have commented themselves that they have been too relaxed and complacent since supporting other people and are now reminded for the intensity in support that is required. The team have also commented how complex Rose's autism is and are concerned with the mistakes they are making, albeit this is probably part of the course to learn from each other and learn alongside Rose. Staff have also been injured which has resulted in a few change of faces which is a trigger for Rose. Parents are very stressed by Rose's presentation and the changes which is placing more pressure on the team.

Implementing the PBS Holistic Practice framework:

A slightly different approach was taken with this PBS referral. This was due to the challenges within the service. It was important to provide a PBS presence in the service immediately as there was a fear of service breakdown. The lead PBS Practitioner was assigned to work into the service alongside staff and to also build up a relationship with Rose. Due to Rose's curious nature (as she already had familiar staff supporting her), she was keen to engage. The PBS Practitioner was still able to assess Rose's autism, sensory needs and environment without a full assessment and made detailed notes immediately after this session. Five other sessions like this took place. In situ practice development was a real benefit in this situation as staff found understanding the autism theory to actual real life experiences the key to improving practitioner competency.

The findings of these sessions were wrote up into a report and a person centred meeting took place so that the staff could reflect on their practice whilst also learn from the report itself. Areas that were covered in the workshop included

- Understanding Rose's autism profile e.g. how this affects her.
- Cognition – understanding and learning.
- Social Communication and use of visual planners and social stories.
- Sensory Processing and strategies to embed into the PBS Plan.
- Motivational Scale Assessment e.g. a shortened version of a functional assessment was conducted with both Rose and staff involvement.

Each one of the above areas involved reflecting on events and learning what went really well rather than what didn't.

PBS Practitioner met with parents and social worker to feed this information back to ensure they were fully involved in the process.

Findings of implementing the PBS Holistic framework:

- Motivational assessment indicated SENSORY as the dominant behaviour function which feeds into communication processing, transitioning and inflexibility in change feeding into difficulty in problem solving.
- Too much 'unstructured down time'. These voids would result in Rose using her IPad to stimulate herself, albeit negatively.
- Too much freedom in her structure. Rose has come from a highly structured school environment. Moving into adult services where choice is considered more freely has probably been too much of a transitional leap for Rose. Choice needs to be narrowed down to two specific choices when offered. This will be more manageable for her.
- Social stories appear to be a valuable tool for Rose however there was too much time where autism practitioners' assumed that Rose understood. Rose was demonstrating 'context blindness' which caused her to become highly anxious.
- Rose being offered too much information.
- Rose did not understand safety in the car and the consequences of this.
- Negative indicators of wellbeing were identified, e.g. avoiding eye contact, muttering under her breath, going to lie on her bed, focusing on her IPad etc.

PBS Strategies Implemented:

- Information again needed narrowing down, e.g. only to be informed of a visitor 30 minutes prior to the event. Staff would check with the visitor the time of arrival and provide Rose with a social story 30 minutes prior also. This reduced possible risks in delayed timing for the visitor and also helped Rose prepare mentally for the visit.
- A social story about car safety was given to Rose.
- Weighted blanket offered to help emotionally regulate Rose when she was anxious. This was provided as soon as staff observed certain negative indictors of wellbeing.
- Visual timetable was amended to reduce choice but ensured that Rose's favourite activities were incorporated.
- More sensory activities were included on timetable e.g. swimming, swings at the park, rebound therapy.
- Structured morning & evening timetable which help regulate Rose's anxieties. These were considered the hot spots in her day and would then have a knock on effect in her life.
- Choice was structured: the PBS Practitioner analysed incidents and found that certain activities appeared to lessen potential aggression, e.g. on an evening Rose would become stressed when the night shift came on shift and would often nip and scratch them. A choice strategy was introduced 15 minutes before night shift arrived of 2 activities e.g. board game or nails painted. Staff knew Rose would not pick the board game and loved having her nails painted. Their person centred knowledge of Rose had identified that Rose does not like to touch anything for a few hours after having her nails painted. This strategy would hopefully reduce the assaults to night staff.
- PBS plan incorporated all of the above strategies.

Outcome(s) to increase quality of life:

The following outcomes were achieved within one month:

- No assaults to night staff.
- No further assaults to staff whilst in the car. Still appears anxious but social story is helping.

- Visual timetable has helped although Rose is trying to move the boundaries e.g. removing her original choice and placing a choice that is difficult to achieve e.g. going to the swimming pool at the times when the slide is not operational. Social stories are being used to explain this.
- Environment is more structured and staff are being more sensitive to Rose's sensory needs. This has resulted in staff pre-empting the need to use the weighted blanket.
- Small sensory room has been designed and Rose is using this occasionally when she needs to regulate herself. This demonstrates that Rose understands the use of the room and is more self-determined in implementing her PBS strategies.
- No incidents have caused injury to staff.
- Incidents still occur however have only needed 2 staff present. This demonstrates a reduction in severity.
- Rose is initiating completing her visual morning and evening planer with staff.
- Staff have identified more negative indicators of wellbeing and included these in Rose's PBS plan.
- 3 incidents have occurred in the past month however none of which were restrictive. Key strategy used in all 3 incidents involved offering space, sensory room and weighted blanket.
- Visits with family members are more relaxed and positive. Parents still remain anxious although recognise a positive change in Rose's wellbeing.

Is there evidence of sustaining/improving quality of life? Post Response:

- A further 3 incidents the following month and remains non-restrictive.
- Social stories are regularly used and proving effective. Staff are becoming competent in using these.
- More theory and practice work identified by the team so a further person centred workshop has been organised.
- No incidents involving change in night shifts.
- No incidents involving recording on her IPad. Possibility due to less 'down time'.
- Sensory strategies have been integrated into her daily routines so that Rose doesn't need to seek these out.
- Lots of community outings and no incidents have occurred.
- Staff have noticed that Rose is sleeping and eating better.

Pen Portrait

Name	Ann	**Diagnosis**	Autism /Moderate Learning Disability/ Bi-Polar
Age	58	**No. of Autism Practitioners**	26

Pen Portrait:

Ann lives in a supported living home with 3 other tenants, some of which have a more severe learning disability to Ann. Ann has lived here since 2011 and has had numerous different placements over the years which all broke down due to her challenging and unpredictable behaviours. Ann has 1:1 support in the home and 2:1 support in the community.

How autism impacts on the person's quality of life:

Ann needs familiarity in her environment and especially needs to know who is supporting her each day. This can build in anxiety the day before and it is important that she has a visual planner so that she understands sequence of events and the names of familiar people each day. If there is a change to this routine, Ann can become extremely anxious which can become aggressive towards staff and her peers.

Current behaviour presentation:

When Ann is feeling anxious she will present with the following behaviours: throwing objects out of her bedroom into the garden and corridor, smearing, stripping off her clothes, urinating, hitting, kicking and pulling hair. It is very difficult to engage Ann in conversation at these times and she is unable to express her emotions in any other way than behaviour. More recently Ann has appeared depressed and refused to get out of bed. When staff encourage her to get up she will become aggressive which can then last for hours into days.

Challenge(s) within the Service:

There has been a lot of sickness in this team over the past several months. There has also been a recruitment drive and the introduction of 4 new staff to the team who have undergone induction training. All staff have completed autism training although this was 2 years ago. Two of the other tenants have also recently been diagnosed with early onset dementia. The anxiety within the team is high due to not knowing what the future will be for these two tenants. The team are very set in their ways and there are a number of very dominant staff members who consider themselves as very knowledgeable about autism and Ann's person centred needs.

Implementing the PBS Holistic Practice framework:

A PBS referral was made to the PBS Lead Practitioner who visited the service to meet Ann and also meet with the manager who initiated the referral. The PBS Practitioner was able to read incident reports, daily records and reflections and also health records. It was evident that staffs' understanding of what constituted an incident was not clear as Ann was

also observed becoming anxious in her home whilst staff were attempting to calm and divert her. Staff commented that this was not an incident and therefore did not record this. As a result behaviour baseline measurements were not able to be captured however As required medication was more accurate therefore this became the priority aim to reduce. The following actions were agreed:

- General health check to rule out any underlying health problems;
- Naturalistic Observations of Ann in her home where she feels most comfortable;
- Functional behaviour assessment e.g. is the unmet need Sensory, Attention, Escape or Tangible;
- Autism/Sensory Processing assessment;
- Environmental assessment;
- Practitioner to attend next staff meeting to evaluate values, attitudes and practice customs;
- Design of the PBS plan;
- Person centred workshop to disseminate plan;
- Periodic review of the plan to measure baseline

Findings of implementing the PBS Holistic framework:

The referral took longer than most referrals due to a number of factors outlined below:

- Functional assessment identified Tangible and Attention as the functions of Ann's behaviours.
- Environmental assessment identified numerous pollutants e.g. noise, unplanned structure, staff only seeing the behaviour and not Ann's anxieties, consequences used e.g. if Ann becomes anxious before she goes out, staff will then not support her on the outing presuming the outing will fail, staff presuming Ann understands everything.
- Lack of varied activities.

PBS Strategies Implemented:

- Structured activity planner that was placed on Ann's bedroom wall. This was visual and Ann was involved in designing this and attractive colours, patterns and designs where used which Ann chose. Ann therefore understood this was her planner and no one else's. Staff were informed that they needed to consistently work to this planner to avoid uncertainty for Ann. Any change needed to be visually communicated to Ann whilst always offering her a 'special' activity as a replacement. Something that she really enjoys.
- Practice observations were used to help staff draw out and identify the environmental pollutants, e.g. when Ann was watching the TV staff would be talking or even stand in front of the TV. Staff learned better in situ and also appreciated how this would impact on Ann's behaviour.
- Ann's key workers supported the development of the PBS plan alongside the PBS Practitioner.
- Person centred workshop to address Ann's cognition and how she learns best. Staff were trained in Working Memory and evaluated how this can impact on Ann, e.g. Ann has difficulty transferring a new skill in different environments and may even forget the entire activity/skill. Staff were taught about repetition and constant explanation. This supported Ann's need for more attention.
- Three other person centred workshops were required to support staffs' understanding of Ann's autism but also to bridge the understanding of her autism

into realistic and successful strategy outcomes. The PBS Practitioner worked into the service alongside Ann and the team to promote this.

Outcome(s) to increase quality of life:

The following outcomes were achieved over the next 3 months:

- Initially Ann did not show any signs of improvement however it was noticeable that she was testing the consistency of staff members knowing that some would not be as consistent due to her confidence. This was still considered a positive outcome as it demonstrated Ann was aware of the changes and the PBS Practitioner could then focus on these staff members to develop their confidence.

- Ann needed some reminding about using her visual planner however she soon would inform staff what was happening before they initiated this conversation. This demonstrated she understood the value this played in her life.
- As Required medication reduced by 12%. Although it had been hoped that this would have been more, staff were beginning to de-brief and reflect on these incidents where medication was needed. In most cases records demonstrated that staff were able to identify the onset of Ann's behaviour which were consistent with either a Tangible or Attention factor.
- More quality social interaction and social communication was presented by Ann, thus repairing damaged relationships with staff and peers.
- Peers stopped leaving the room if Ann entered.
- Smearing has not occurred at all.
- 5 incidents of stripping off her clothes. There was always an environmental variable e.g. others receiving attention, mother not visiting due to ill health, advocate arriving late and not at the allotted time Ann had expected. This was discussed with the PBS Practitioner and it was evident that staff had identified this first.

Is there evidence of sustaining/improving quality of life? Post Response:

- Environment appeared much calmer and relaxed during a spot check by PBS Practitioner.
- Further work was needed with 2 staff members due to not following Ann's PBS plan. This was evident during reporting analysis. Upon investigating this further staff had not appreciated the importance of the plan and the need for consistency and the impact without this can have on Ann.
- As Required administrations have been sustained at 12% and not increased.
- Ann is now feeling more confident and is planning her first holiday away.
- Staff are appreciating the importance of continuous review and evaluation of Ann's PBS plan.
- The team have since identified the need for sensory processing training in order to support Ann better.

Pen Portrait

Name	Billy	**Diagnosis**	Autism / Down Syndrome
Age	36	**No. of Autism Practitioners**	13

Pen Portrait:

Billy has a lovely personality with a great sense of humour. He can be extremely friendly and inquisitive and loves to be centre of attention and enjoys the attention this receives. Billy has lived in a number of different residential and supported living services and on each occasion his behaviour has resulted in the social care providers serving notice on his tenancy due to physical (quite serious) assaults towards his peers and staff members. On many occasions this would result in police involvement in order to control his aggression. Billy has 2:1 staff support which can increase to 5 during crisis episodes in his behaviour.

How autism impacts on the person's quality of life:

Billy is challenged by social relationships and does find it difficult to develop relationships whether this be with his peers or with staff. This can take a long time to develop and will often present with avoidance towards people initially. Billy is able to hold a good level of conversation with people once he is familiar with them. His is challenged daily with understanding fully what people have said to him and he will often only retain certain parts e.g. he may hear the word cinema when staff are talking with other peers and expect to go to the cinema immediately. He has difficulty with understanding the concept of time and is especially challenged when sharing attention or taking turns with his peers. This can be a hot spot for Billy. He also has difficulty when staff try to encourage him to be independent e.g. taking his clothes to the laundry or other household tasks and can display significant behaviours of concern. Billy finds regulating his emotions difficult and finds it difficult to express himself. This can often go unnoticed until he is physically aggressive. He struggles with close contact with peers, which his living environment does not cater for due to living with 3 other people in a small home.

Current behaviour presentation:

Billy's level of aggression can be extremely challenging and historically there have been occasions when he has hospitalised staff members. He is a very powerful man who lacks the capacity to understand the consequences of his actions. Billy can significantly damage the living environment, e.g. ripping doors off, punching holes in walls, throwing chairs and tables. He will not discriminate against whom he assaults and often his peers have unfortunately been caught in the crossfire. Restrictive physical intervention is difficult to implementing in a small environment, especially when there are 5 support staff trying to safeguard him and themselves. There have been times when even 5 staff has struggled to maintain safety in restraint which them results in police intervention. Billy can become even more anxious during these times and has been known to be strapped by police in order to control his aggression safely. Billy has had in the past 4 weeks 15 restrictive physical interventions, averaging 13 minutes in restraint with high intensity. Most incidents centred around the kitchen or hallway next to a peers flat door.

Challenge(s) within the Service:

There are significant environmental challenges due to the homes layout and lack of space. The garden is often used so that Billy can have more space and to also get away from the repetitive noises of another peer who will often use these noises when Billy is agitated. The team have a very basic understanding of Billy's autism and downs syndrome and do not really appreciate the significance these conditions have on Billy or his behaviour presentation. The material environment is bland and shows areas of maintenance work due to holes being punched in walls, pictures have been taken down and walls patched up. Billy does not like curtains in his rooms so this makes the environment even barer. Part of the team is very committed to making this work for Billy while others feel that he was wrongly placed. Tensions are present within the dynamics of the team.

Implementing the PBS Holistic Practice framework:

A PBS referral was received by the PBS Lead Practitioner. The PBS Lead identified a Practitioner within the PBS Team who not only had experience of autism but also of downs syndrome. The PBS Practitioner visited the service and met with key staff, spoke with Billy, observed him in his environment and reviewed incident records, support planning and risk management. The following actions were:

- Environmental needs assessment
- Sensory Processing assessment (based on the Winnie Dunne model for people with autism and co-existing conditions)
- Motivational Scale Assessment – functional behaviour assessment
- To amend risk assessment to safeguard Billy and staff in reactive stage of the behaviour arousal cycle
- Meeting with the staff team to listen to their views. This was not intended to be a person centred workshop at this time as they were not in a place to receive this positive and creative session. They firstly needed to de-brief
- Activity planning and organising structure
- To observe the interactions between Billy and his peers

Findings of implementing the PBS Holistic framework:

There were a number of outcomes that informed practice and provided staff with new knowledge:

- Staff were aware that Billy struggled being in an environment with one of his peers but did not have the context to this. The other tenant talks very loudly which Billy clearly did not like. He also struggled with sharing the attention of staff with his peer. Staff would naturally divert their attention to the other peer when he spoke to staff. This is the onset to Billy's anxieties, which he is unable to express.
- Billy had no boundaries or expectations.
- There was a power struggle between Billy and staff of putting curtains back up and then Billy would pull them down. This was clearly a sensory related issue which staff had not identified.

PBS Strategies Implemented:

- Strategies in place for when the other tenant wanted to engage with Billy's staff, e.g. organising the kitchen environment so that there are little times when they are in there together. The staff supporting the other tenant would also interject to divert the tenant away so that Billy's staff could focus on him.

- In previous settings support staff would do most things for him however this service aims to increase independence and motivation. A social story was created to communicate this with Billy. Billy would be given one verbal prompt of encouragement to do a task. If he chose not to respond staff would move onto the next activity but would not do the task for him. This meant that clothes started to pile up however as Billy could see that staff would not do this he started to initiate these tasks, as he does not like an untidy environment.
- Privacy glass was installed in Billy's room so that it would account for no curtains up. Billy loved a particular football club so staff commissioned an artist to draw the clubs motif around his window to make it less bare.
- Visual activity planner developed with Billy. Billy had some excessive weight which needed managing so long walks were introduced, which Billy enjoyed. This eventually led to riding a trike on cycle tracks and a riding club being introduced with competitions. Billy always won something!

Outcome(s) to increase quality of life:

The following outcomes were achieved by the 4 weeks stage:

- 6 incidents where restrictive interventions were needed. 3 of which involved the kitchen environment. These incidents identified that not enough attention from the staff was in place, which allowed for the other tenant to engage with Billy's staff. The structured timetable had also not been followed consistently. A de-brief took place with the staff involved who were able to recognise this. There was also an incident during a cycle ride which did not lead to a restrictive intervention however it appeared that Billy had not had enough processing time to understand what was happening.
- Billy had lost 2st in weight.
- No incidents of aggression centred around curtains.
- Average duration reduction in incidents by 53%.

Is there evidence of sustaining/improving quality of life? Post Response:

- Billy has since refused to go on bike rides after 2 months of the PBS plan. During a periodic review with staff they feel this is because he is getting bored of bike rides and have introduced another 2 activities, e.g. going to the gym and wall climbing both of which can maintain exercise and also help reduce frustrations. Bike rides are still an option rather than taking this away completely.
- Billy has the other tenant have both completed an outward-bound activity course to try and build bridges and engage with each other positively.
- PBS Practitioner has undertaken regular de-brief sessions and held person centred workshops so that staff can understand the context in which Billy's behaviour is socially constructed.
- Manager and seniors have completed PBS Leadership course.
- Currently training one PBS Practitioner who works in the service.
- Baseline behaviours have remained constant with no increase or decrease. Staff however, believe this will reduce with more time which is an indicator of their mind-set shifting.

UNIVERSITY OF SUNDERLAND

Please read each of the questions below and place a tick in the box that best describes your opinion. Please relate these questions to the last month of your work.

Focus Group	
Region	
Participant Ref No.	

Study Title: *A Holistic Positive Behaviour Support Practice Framework for Autism Practitioners*

No.		*Strongly disagree (1)*	*Disagree (2)*	*Neutral (3)*	*Agree (4)*	*Strongly Agree (5)*
Theme	Specific Knowledge					
1	I understand why service users present with behaviours of concern.					
2	I understand how autism impacts on service users lives.					
3	The PBS policy provides me with an understanding of how to support people with autism who may challenge.					
Theme	Attitudes & Experiences					
4	My attitude (and those of my team) positively affects outcomes e.g. quality of life for service users.					
5	I am able to use my experiences positively to improve my practice when supporting people who challenge.					
6	There is an attitude of reducing restrictive practices.					
Theme	Competencies					
7	I am capable of implementing proactive PBS strategies to reduce behaviours of concern from escalating.					
8	I am able to safely support a service user and those around them when they present with behaviours of concern.					
9	I know how to create an autism specific environment for the service users I support.					
Theme	Practice Standards					
10	Service Users' behaviour plans provide the necessary information to know how to support them according to their needs.					
11	I understand what is expected of me to ensure service users' rights are maintained, especially when they present with behaviours of concern.					
12	Our current practice standards provide me with confidence that I am providing good support.					
13	Current training for my service is appropriate for the people I support.					
Theme	Service Outcomes					

14	There is a focus on the person and not their behaviour.					
15	Restrictive practice, e.g. restraint is a daily occurrence in the service.					
16	Service Users' are not restricted in their skills and independence as a result of their behaviours of concern.					
Theme	Monitoring practice performance					
17	Incident recording and reporting is clear and objective.					
18	Incident reporting leads to more proactive management behaviour.					
19	I am offered a de-brief after an incident.					
20	The monitoring systems that are currently in place help us to reflect and learn how to improve our clinical practice.					

Thank You

Code List from Semi Structured Interviews:

1st Semi Structured Interview								Code Ref No	Coding Description	2nd Semi Structured Interview							
S	A	D	H	J	R	E	G	**CODE 1**	Supporting services for people with autism and learning disabilities	S	A	D	H	J	R	E	G
					R			**CODE 2**	Liaising with Commissioning or Statutory Bodies	S	A		H				
S	A	D	H	J	R		G	**CODE 3**	Winterbourne has shaped national policy and damaged reputation of social care								
S	A	D	H	J		E		**CODE 4**	Social care system is failing and it's not just about Winterbourne View	S							
S	A	D	H	J	R	E	G	**CODE 5**	Local authority financial cuts but high expectations on delivery								
S	A	D	H	J	R	E	G	**CODE 6**	Local authority lack resources of action								
		D					G	**CODE 7**	Winterbourne clouds professionals' judgements								
S	A	D					G	**CODE 8**	Policy focuses too much on what has gone wrong rather than how we put it right								
S	A			J			G	**CODE 9**	The Care Act/Health & Social Care Act		A						
S	A		H					**CODE 10**	Behaviour regulations get lost in policy or offers little practical understanding		A	D					
								CODE 11	New policies updated to take account of new legislation e.g. PBS & Autism which are then built into practice development	S	A		H	J		E	
		D						**CODE 12**	DH Positive & Proactive Care is influencing practice and policy	S		D	H	J	R	E	G
								CODE 13	Skills for Care/NICHE guidance is helping to develop good practice and this is embedded into the PBS framework	S	A	D	H			E	G
	A	D						**CPDE 14**	Autism Strategy has helped inform/improve environments	S		D		J		E	
S	A	D		J	R	E		**CODE 15**	Lots of new guidance but the community is still left interpreting it with mixed understanding								
								CODE 16	Disparity in PBS understanding in other organisations	S		D				E	
S	A		H		R	E		**CODE 17**	Crisis breakdowns and serving notice on contracts/service users								
								CODE 18	MCA/DOLS	S	A	D	H	J			
S	A	D	H					**CODE 19**	Challenging Behaviour Policy								

		D						**CODE 20**	Organisational policies are poorly written and leave gaps in how to apply in practice								
S	A		H					**CODE 21**	No current practice standards available nationally								
	A	D		J				**CODE 22**	Local Authority Autism Leads have made little impact								
S	A			J				**CODE 23**	Reliance on Behaviour Specialist Teams who are already over stretched								
	A			J	R	E	G	**CODE 24**	Long delays in Behaviour Team referrals and often inconsistency in support causing time consuming delays in people's quality of life								
	A	D	H			E		**CODE 25**	Managers/Staff not knowing what to do when a person presents with a behaviour of concern								
	A	D	H					**CODE 26**	Fragmented lives of people with autism								
	A	D	H	J	R	E	G	**CODE 27**	Leaders lack current knowledge of autism/PBS and leads due to needing more generic leadership skills which leads to misunderstandings or misperceptions of practice								
S		D		J	R			**CODE 28**	Corporate responsibility of PBS/Autism Practice								
S		D	H	J		E		**CODE 29**	Social Care Governance group collate incident management statistics	S							
S		D						**CODE 30**	Board of Management are informed of incident management statistics	S							
S		D	H	J				**CODE 31**	H&S team review incidents	S							
S	A	D		J	R		G	**CODE 32**	Recording & Reporting of Incidents								
S	A	D						**CODE 33**	Managers monitor all incidents								
S	A		H					**CODE 34**	Incident reports submitted within 24 hours								
S	A	D		J	R			**CODE 35**	Delay in reporting of incidents or monitoring								
								CODE 36	Membership to Social Care Governance group for managers								
S			H				G	**CODE 37**	Quality of incident reports can be poor								
	A						G	**CODE 38**	Staff not understanding the importance of reporting								
S	A	D						**CODE 39**	Managers are overwhelmed by numbers of incident reports to monitor and don't get time to check them all								
S		D						**CODE 40**	Leadership and dissemination of information not a focus/priority								
								CODE 41	Physical Intervention Trainers not understanding PBS								
		D	H	J			G	**CODE 42**	Policies distributed without guidance from leaders or managers								

	A				R	E		**CODE 43**	Specialist advisors in organisations who take responsibility and offer advice and guidance on behaviour	S							
S	A	D	H	J	R			**CODE 44**	Management induction in place but does not cover PBS and/or autism								
S	A			J	R			**CODE 45**	Challenging Behaviour & Autism training is mandatory but out dated and focuses too much on physical intervention and breakaways								
			H	J	R			**CODE 46**	Managers often last to receive updated training and don't understand behaviour								
S	A	D	H	J				**CODE 47**	Staff focus on behaviour and don't respond well to it so the quality of the service is affected (including the lives of people with autism and the staff themselves)								
S	A	D	H	J	R	E	G	**CODE 48**	Practical knowledge and application of PBS and autism practice is acknowledged as out of date or poor								
S	A		H					**CODE 49**	Relationship & Partnership working								
	A	D	H			E		**CODE 50**	Lack of staff morale influences the lives of people with autism, negatively								
S	A	D	H	J		E	G	**CODE 51**	Staff sickness due to burn out (e.g. stressed, tired, worried, panic) or are injured as a result of service user behaviour								
		D	H		R			**CODE 52**	Expectation that staff should manage challenging behaviour irrespective of how this makes them feel								
S	A	D						**CODE 53**	Recruitment shortages due to low wages								
S	A	D	H	J	R	E		**CODE 54**	Negative staff values & attitudes that affect culture and practice	S							
S	A	D		J	R	E		**CODE 55**	More restrictive practices and rights being affected								
S		D		J				**CODE 56**	Negative relationships with professionals or between managers and staff								
S	A			J	R			**CODE 57**	Lack of quality of life opportunities for service users								
S	A	D		J				**CODE 58**	Increased behaviours of concern								
	A			J		E		**CODE 59**	High turnover of staff leading to inconsistencies and lost historical information about the service user								
S	A		H	J			G	**CODE 60**	Lack of time to reflect on policies and practice								
				J				**CODE 61**	Learning from mistakes and reflective practice is poor								
S		D		J	R		G	**CODE 62**	Staffing and attitudes affect person centred practices								

S			H	J	R	E	G	**CODE 63**	Lack of good autism practice and role modelling									
	A	D	H		R			**CODE 64**	Staffs knowledge of PBS and autism is limited									
S	A	D		J	R	E	G	**CODE 65**	Un-stimulating environment or damaged environment/Not appropriate accommodation for service user needs									
	A	D			R		G	**CODE 66**	Excessive amounts of paperwork that takes staff away from supporting service users									
S	A	D	H	J	R	E	G	**CODE 67**	Compassion, dignity, respectful, freedom of liberty, choice & independence	S	A	D	H	J	R	E	G
S	A		H	J	R	E	G	**CODE 68**	Person centred planning & approaches	S	A	D	H	J	R	E	G
	A	D	H		R			**CODE 69**	Peer workshops & Team Meetings									
S	A	D	H	J		E	G	**CODE 70**	To understand how to use behaviour assessments	S	A							
S	A	D	H	J	R	E	G	**CODE 71**	Knowing what interventions to try following assessments so that it is relevant to the person and their autism	S	A							
S				J	R			**CODE 72**	Review of service against Regulations		A	D						
S	A		H	J	R	E		**CODE 73**	To improve practice	S		D	H					
S	A		H	J		E	G	**CODE 74**	To inform staff why we are doing what we are doing	S	A	D						
								CODE 75	Better understanding of autism issues that has changed practices and approaches to accommodation & support needs	S	A	D	H	J		E	G
								CODE 76	Implementing autism assessments and embedding into planning	S	A	D	H	J	R	E	G
								CODE 77	Clinically and ethically valid support resulting in good autism practice	S	A	D	H	J	R	E	G
S		D	H				G	**CODE 78**	Strong added value to service providers	S	A	D	H					
	A		H					**CODE 79**	How to design and write PBS and autism planning	S		D	H				G	
								CODE 80	Broader understanding of policy and practice in PBS and autism services	S	A	D		J	R	E	G
								CODE 81	Reduces cost to commissioners					J				
								CODE 82	PBS Referral System offering a responsive and supportive service	S	A	D	H	J			G
								CODE 83	Practice is focusing on the person and not the behaviour	S	A		H	J	R		G
								CODE 84	Governance (including quality assurance) is more robust and everyone is responsible with much cleared roles	S	A	D	H	J	R	E	G
								CODE 85	Board and Director PBS Leads	S				J	R	E	
								CODE 86	PBS framework is a transparent system	S	A	D	H		R		G

								CODE 87	PBS Practitioners working into services offering practice leadership	S	A	D	H	J	R	E	G
								CODE 88	PBS Leadership workshops	S	A	D		J	R	E	G
								CODE 89	Networking PBS/Autism Practice Groups & Front Line Focus Groups for practice updates and reflection	S		D	H			E	G
								CODE 90	Reflection has become commonplace and so has de-briefing	S	A	D	H	J		E	G
								CODE 91	Policies embedded into practice	S	A						
								CODE 92	Holistic PBS policy	S	A	D	H	J	R	E	
								CODE 93	Leaders positive about PBS	S	A	D		J	R		
		D						**CODE 94**	Leaders need to undertake this training as its improves their own practice and understanding	S			H				
								CODE 95	Identification of toxic environments and hot spot areas	S		D	H		R	E	G
								CODE 96	Contextualised up top date person centred workshops and training helps staff to understand and learn better	S	A	D	H		R	E	G
								CODE 97	Practice standards have improved how services operate and deliver support to people with autism and demonstrates how policy has been implemented in practice	S	A	D	H	J	R	E	
								CODE 98	Evidence based model has improved knowledge and practice	S	A	D	H	J	R	E	
								CODE 99	Improved reporting and recording		A						
								CODE 100	More proactive responses from managers	S	A	D	H	J	R	E	G
								CODE 101	Focus on practice	S	A	D	H	J	R	E	G
								CODE 102	Decline in service challenges notes by managers	S	A	D	H		R		G
								CODE 103	CQC have positively praised PBS practice directly and inspection results have improved as a result	S					R	E	
								CODE 104	Growth has been too quick and has affected quality. The standards will help us to consolidate quality & competency			D					
								CODE 105	PBS has informed practice & delivery through measurable data & ensured services & service users receive better quality			D	H	J	R	E	G
								CODE 106	The framework closes the gap between policy and practice	S		D	H	J			
								CODE 107	Leaders have better understanding	S	A	D	H	J	R	E	
								CODE 108	This model can transfer into other social care provision			D			R	E	
								CODE 109	Empowering service users and staff	S		D	H	J	R	E	G

								CODE 110	Reduction in the need for Behaviour Team interventions	S	A					E	
								CODE 111	Reduction in toxic environments	S	A	D	H		R		G
								CODE 112	Reduction in behaviours of concern & restrictions	S	A	A	H		R	E	G
								CODE 113	Better well being of service users	S	A	D	H		R		G
								CODE 114	Better well being of staff/managers (including improved values and attitudes, sickness and turnover)	S	A	D	H	J	R		G
								CODE 115	More common and professional language	S	A	D	H	J	R		G
								CODE 116	More confident staff team	S	A	D	H	J	R		G
								CODE 117	Improvement in role modelling of good practice	S	A	D					
								CODE 118	Overall service quality has improved	S	A	D	H	J	R	E	G

COMPARISONS OF SEMI-STRUCTURED INTERVIEWS

Question Theme	Leaders 1st Interview	Leaders 2nd Interview
Policy	"Policy focuses too much on what has gone wrong rather than how we put it right". "Social care system is failing and it's not just about Winterbourne View". "Organisational policies are poorly written and leave gaps in how to apply in practice". "Lots of new guidance but the community is still left interpreting it with mixed understanding". "Winterbourne has shaped national policy and damaged reputation of social care". "Behaviour regulations get lost in policy or offers little practical understanding". "Challenging Behaviour Policy".	"DH Positive & Proactive Care is influencing practice and policy". "Skills for Care/NICHE guidance is helping to develop good practice and this is embedded into the PBS framework". "Broader understanding of policy and practice in PBS and autism services". "The framework closes the gap between policy and practice". "Practice standards have improved how services operate and deliver support to people with autism and demonstrates how policy has been implemented in practice". "Holistic PBS policy". "Broader understanding of policy and practice in PBS and autism services".
Philosophy & Principles of support	"Compassion, dignity, respectful, freedom of liberty, choice & independence". "Fragmented lives of people with autism". "Relationship & Partnership working". "Negative relationships with professionals or between managers and staff".	"Compassion, dignity, respectful, freedom of liberty, choice & independence". "Reduction in behaviours of concern & restrictions". "Better well being of service users". "Better well being of staff/managers (including improved values and attitudes, sickness and turnover)".

Leadership & Governance	"Managers are overwhelmed by numbers of incident reports to monitor and don't get time to check them all". "Staff not understanding the importance of reporting". "Managers monitor all incidents". "Delay in reporting of incidents or monitoring".	"Governance (including quality assurance) is more robust and everyone is responsible with much cleared roles". "Board and Director PBS Leads". "PBS framework is a transparent system".
Dissemination of Knowledge	"Leadership and dissemination of information not a focus/priority". "Physical Intervention Trainers not understanding PBS". "Policies distributed without guidance from leaders or managers". "Peer workshops & Team Meetings". "Local Authority Autism Leads have made little impact". "Long delays in Behaviour Team referrals and often inconsistency in support causing time consuming delays in people's quality of life".	"PBS Practitioners working into services offering practice leadership". "Networking PBS/Autism Practice Groups & Front Line Focus Groups for practice updates and reflection". "Policy embedded into practice". "Contextualised up to date person centred workshops and training helps staff to understand and learn better". "More confident staff team".
Leader & Managers Knowledge of PBS	"Leaders lack current knowledge of autism/PBS and leads due to needing more generic leadership skills which leads to misunderstandings or misperceptions of practice". "Managers/Staff not knowing what to do when a person presents with a behaviour of concern". "Management induction in place but does not cover PBS and/or autism". "Challenging Behaviour & Autism training is mandatory but out dated and focuses too much on physical intervention and	"Leaders have better understanding". "Reduction in toxic environments". "Improvement in role modeling of good practice". "More common and professional language". "PBS Leadership workshops". "How to design and write PBS and autism planning".

	breakaways". "Managers often last to receive updated training and don't understand behaviour". "Practical knowledge and application of PBS and autism practice is acknowledged as out of date or poor".	
Experiences & Challenges	"High turnover of staff leading to inconsistencies and lost historical information about the service user". "Lack of time to reflect on policies and practice". "Staffing and attitudes affect person centred practices". "Lack of good autism practice and role modeling". "Excessive amounts of paperwork that takes staff away from supporting service users". "Crisis breakdowns and serving notice on contracts/service users".	"Practice is focusing on the person and not the behaviour". "Overall service quality has improved". "Strong added value to service providers".

Components of a toxic environment	"Un-stimulating environment or damaged environment/Not appropriate accommodation for service user needs". "Negative staff values & attitudes that affect culture and practice". "More restrictive practices and rights being affected". "Lack of staff morale influences the lives of people with autism, negatively". "Staff sickness due to burn out (e.g. stressed, tired, worried, panic) or are injured as a result of service user behaviour ". "Lack of quality of life opportunities for service users" "Staff focus on behaviour and don't respond well to it so the quality of the service is affected (including the lives of people with autism and the staff themselves)"	"Practice is focusing on the person and not the behaviour". "Identification of toxic environments and hot spot areas". "Reduction in toxic environments". "Autism Strategy has helped inform/improve environments". "Decline in service challenges noted by managers".
Addressing toxic environments	"Practical knowledge and application of PBS and autism practice is acknowledged as out of date or poor". "Specialist advisors in organisations who take responsibility and offer advice and guidance on behaviour". "Reliance on Behaviour Specialist Teams who are already over stretched". "Recording & Reporting of Incidents". "Expectation that staff should manage challenging behaviour irrespective of how this makes them feel".	"Contextualised up top date person centred workshops and training helps staff to understand and learn better". "Empowering service users and staff ". "Person centred planning & approaches". "Better understanding of autism issues that has changed practices and approaches to accommodation & support needs". "Implementing autism assessments and embedding into planning". "Reflection has become commonplace and so has de-briefing".

Practice Standards for the Community of Practice	"To improve practice". "To inform staff why we are doing what we are doing". "Growth has been too quick and has affected quality. The standards will help us to consolidate quality & competency". "No current practice standards available nationally". "Knowing what interventions to try following assessments so that it is relevant to the person and their autism".	"Practice standards have improved how services operate and deliver S support to people with autism and demonstrates how policy has been implemented in practice". "PBS has informed practice & delivery through measurable data & ensured services & service users receive better quality". "Better understanding of autism issues that has changed practices and S approaches to accommodation & support needs". "Clinically and ethically valid support resulting in good autism practice". "CQC have positively praised PBS practice directly and inspection results have improved as a result".

Code List from Focus Groups:

1st Focus Group				%	Code Ref No	Coding Description	%	2nd Focus Group			
A			D	50%	**CODE**	Not really sure that it actually is communicated to the workforce.					
A	B	C	D	**100%**	**CODE**	Email sent out to managers informing of a policy update.					
A	B		D	75%	**CODE**	Manager is meant to discuss policy update in meetings but we often don't have meetings for months due to being short staffed.					
A		C		50%	**CODE**	Directors and Managers are often at a loss with what to do when a service user presents with behaviour.					
	B	C	D	75%	**CODE**	Manager audits paperwork on a weekly basis and monthly on numbers of incidents.					
	B	C	D	75%	**CODE**	Key workers write a monthly summary, which includes behaviour and this is sent to the manager and used for inspections.					
		C	D	50%	**CODE**	Health and safety meeting checks reports/audits.					
	B	C	D	75%	**CODE**	Risk assessments.					
A	B	C	D	**100%**	**CODE**	Compatibility is a daily challenge or incidents are related to incompatibility.					
A	B	C	D	**100%**	**CODE**	Small group homes can cause behaviours.					
A	B	C		75%	**CODE**	Staff do not have involvement in assessments/referrals and people are often placed without staff having the time to read assessment profiles.					
	B	C	D	75%	**CODE**	Crisis admissions.					
A	B	C	D	**100%**	**CODE**	Staffing levels need to be higher.					
A	B		D	75%	**CODE**	Have to pull staff from other services to support an aggressive person. Staff often get hurt because of this.					
A		C	D	75%	**CODE**	Commissioners will not fund any more support hours for service users.					
			D	25%	**CODE**	Recruitment and getting the right type of person.					
A	B	C	D	**100%**	**CODE**	No breaks and working long hours due to staff sickness.					

A	B	C		75%	**CODE**	Positive staff moods rub off on service users.					
A	B		D	75%	**CODE**	The service users can really pick up on the moods of staff when they are feeling down, tired or negative.					
A		C	D	75%	**CODE**	Staff get disheartened especially when it comes to person centred approaches as staff are unable to provide the time due to commissioners only funding so many hours. This results in challenging behaviour.					
		C	D	50%	**CODE**	Staff led rather than person centred for service users.					
			D	25%	**CODE**	Maintain service users rights.					
		C	D	50%	**CODE**	Focus on behaviour due to becoming stressed/more restrictive practice.					
A			D	50%	**CODE**	More pressure on staff without any service payment.					
A	B	C	D	**100%**	**CODE**	Staff do become de-motivated and undervalued because the pressure is more but the pay isn't.					
	B	C	D	75%	**CODE**	Lose objectivity when values and attitudes are affected.					
A	B	C	D	**100%**	**CODE**	No time to read and digest plans or policy.					
		C	D	50%	**CODE**	Lack of confident staff.					
A				25%	**CODE**	Low turnover in teams that have good cohesion.					
A	B		D	75%	**CODE**	Small homes create a domino effect with other service users behaviours.					
A	B	C	D	**100%**	**CODE**	Person centred approaches helps spot the early signs/better outcomes for service users.					
		C	D	50%	**CODE**	Use communication tools.					
		C	D	50%	**CODE**	Use physical intervention as a last resort/more PI.					
A	B	C	D	**100%**	**CODE**	Write an incident report.					
A	B		D	75%	**CODE**	No trigger to behaviour incident.					
A	B	C		75%	**CODE**	One staff member takes the lead in supporting a service user who is challenging. Confidence.					
A	B		D	75%	**CODE**	Sometimes we just don't know what is wrong so we just have to see the behaviour through. We often feel helpless.					
A	B		D	75%	**CODE**	We don't think we understand autism as much as we should so we are left to figure the					

						behaviours out ourselves. We often talk about this as it's a huge problem					
A	B		D	75%	**CODE**	Its great sitting in a classroom learning about autism but it seems so different when you see it through our own eyes.					
A	B	C	D	**100%**	**CODE**	Specialised training never really hits the spot or not enough training.					
A	B	C	D	**100%**	**CODE**	Physical intervention training.					
		C	D	50%	**CODE**	How to write behaviour plans.					
	B	C		50%	**CODE**	Not enough money for activities. Service users are boarded.					
	B	C		50%	**CODE**	When new things don't work staff go back to their old ways.					
		C	D	50%	**CODE**	Old cultures not challenged.					
	B			25%	**CODE**	When we don't understand something that is not answered for months we start to make judgements.					
			D	25%	**CODE**	Behaviour specialist nurse. Offers training but not often due to work load.					
A	B	C	D	**100%**	**CODE**	Challenging behaviour training, which is refreshed every 2 years.					
	B	C	D	75%	**CODE**	Specialised training in autism and behaviour that is specific to our service users.					
A	B	C	D	**100%**	**CODE**	We need incident recording training. We constantly get pulled up for not getting it right but we have never been trained.					
	B	C	D	75%	**CODE**	We need de-briefing training.					
A	B	C	D	**100%**	**CODE**	Very little opportunity to input into PBS plans as the manager tends to write these					
A	B	C	D	**100%**	**CODE**	The assessment is normally done before the service user moves in but we've never seen any of that information.					
A	B		D	75%	**CODE**	Staff read the draft behaviour plan and can add things.					
	B	C	D	75%	**CODE**	Staff are often in conflict with what managers write in the behaviour plan. We know the service users better so we should be involved in writing the plans.					
	B	C	D	75%	**CODE**	Strategies don't make sense we they are not used in most part/Often left to judgement call.					
	B	C	D	75%	**CODE**	Strategies don't say how to implement them/Inconsistencies in implementation.					
	B	C		50%	**CODE**	Strategies inconsistent with autism needs/lack of knowing this.					

A	B		D	75%	**CODE**	Often left wondering why a behaviour happened.						
A		C	D	75%	**CODE**	Professionals don't know what to do sometimes either so we are left to just get on with it.						
A				25%	**CODE**	Right support not given until serious incident occurred.						
A	B	C	D	**100%**	**CODE**	Records don't help to understand the service user better as this is not done. We don't get feedback.						
A	B	C	D	**100%**	**CODE**	The team doesn't get to discuss incidents. No time to reflect.						
	B	C	D	75%	**CODE**	Our experiences help us more than the records/we help each other by sharing our experiences.						
	B	C	D	75%	**CODE**	The paperwork doesn't help us to understand why behaviour has occurred.						
A		C		50%	**CODE**	We don't get adequate de-briefs or only get them when something big happens.						
A	B	C	D	**100%**	**CODE**	Practice standards: We would have a better understanding of what to do.						
	B	C	D	75%	**CODE**	Reduce physical interventions						
	B	C	D	75%	**CODE**	Understand the behaviour better						
	B	C	D	75%	**CODE**	Avoid people getting hurt or going into crisis						
	B	C	D	75%	**CODE**	Understand autism/behaviour and the person better.						
	B	C	D	75%	**CODE**	Reduce stress in staff/help us to gain confident and reduce stress.						
A		C		50%	**CODE**	Just knowing there is a system there to help is reassurance in itself						
A		C	D	75%	**CODE**	Current training is not enough.						
						2nd Focus Group Session						
					CODE	Focus group session with staff and service users about the policy.	**100%**	A	B	C	D	
					CODE	Safeguarding consulted about policy.	50%		B	C		
					CODE	Experiences of staff and service users were included in the policy.	**100%**	A	B	C	D	
					CODE	Workforce know who the Director is who leads PBS.	**100%**	A	B	C	D	

					CODE	PBS Principles known by the workforce.	50%	A	B		
					CODE	PBS Team established and took part in the policy focus groups.	**100%**	A		C	D
					CODE	Workforce engaged, consulted and empowered	**100%**	A	B	C	D
					CODE	Policy and practice issues can be communicated by workforce to the Lead in PBS.	**100%**	A	B	C	D
					CODE	PBS lead has visited services and sat in on staff meetings to hear experiences.	**100%**	A	B		D
					CODE	Managers have been trained in PBS framework and communicated this back to workforce.	**100%**	A	B	C	D
					CODE	PBS reporting systems in place, which lead attended.	50%		B	C	
					CODE	Managers positive about PBS	**100%**	A	B	C	D
					CODE	Environments adapted to meet the needs of the service users through assessments.	75%	A	B	C	
					CODE	Reduction in incidents between service users.	75%	A	B	C	
					CODE	Staff/Teams have greater objectivity and understanding.	50%		B	C	
					CODE	Service user s' are active.	**100%**	A	B	C	D
					CODE	Less sickness/stress due to staff feeling supported.	50%	A		C	
					CODE	Recognition that less staff or negative attitudes is often better to reduce environmental toxins.	75%		B	C	D
					CODE	Less compatibility issues. Service users' are spending time with each other more constructively.	75%	A	B	C	
					CODE	Placements have been maintained.	50%	A			D
					CODE	Healthy culture and attitudes as staff/managers recognise how toxic environments are created due to attitudes from staff.	**100%**	A	B	C	C
					CODE	More creativity and problem solving.	**100%**	A	B	C	D
					CODE	Performance targets help keep staff focused and supportive of service users goals.	50%	A		C	
					CODE	Staff are motivated and see benefits of PBS.	75%	A	B	C	

					CODE	Culture of reflection and sharing knowledge.	**100%**	A	B	C	D
					CODE	Understanding autism and communication, e.g. visual cues e.g. in assessments or planning.	**100%**	A	B	C	D
					CODE	Contextualised training.	**100%**	A	B	C	D
					CODE	Physical intervention training is only a smaller element as opposed to proactive PBS model.	50%		B	C	
					CODE	Recognition that generic autism training has not worked in the past.	50%	A	B		
					CODE	Holistic framework training is appropriate to the needs of the service users.	75%	A	B	C	
					CODE	Incident reports/records have improved in standards.	75%	A		C	D
					CODE	Recognition from CQC/Professionals on improvements that have been made in practice.	50%	A			D
					CODE	Staff fully involved in assessment process and involved in placement decision.	**100%**	A	B	C	D
					CODE	Planned and controlled admissions, which reduced transition and crisis situations.	50%		B	C	
					CODE	Staff involved in writing PBS plans.	**100%**	A	B	C	D
					CODE	Sense of ownership and morale improvements as a result of PBS.	75%	A	B	C	
					CODE	Focus on the person rather than the behaviour.	**100%**	A	B	C	D
					CODE	Focus on autism and how this impacts on the service user and consider ways of reducing this. Improvement in clinical practice.	**100%**	A	B	C	D
					CODE	PBS plan helps staff to be mindful of gradient approach, rights and restrictions and are related to autism needs.	75%	A	B	C	
					CODE	Clarity in how to implement strategies and reduces inconsistent practice. This reduces incidents as a result.	75%	A		C	D
					CODE	Policy outlines responsibilities in incident recordings. Everyone has a responsibility.	75%	A	B	C	
					CODE	Incident form changed to include the right information for learning.	50%	A	B		
					CODE	De-briefs happen and they are valued.	50%		B	C	
					CODE	Reflection on practice section on incident form.	**100%**	A	B	C	D

					CODE	Staff responses to incidents are better and better governance by management/Directors.	50%	A	B		
					CODE	Overall team wellbeing improved: confident, high morale, improved reports, recognition of improvements by CQC and social workers.	**100%**	A	B	C	D
					CODE	Increased understanding of the reasons for behaviours and the appropriate strategies to use.	75%	A	B	C	
					CODE	Reduced behaviour incidents.	**100%**	A	B	C	D
					CODE	Behaviour is no longer a constraint.	75%	A	B	C	
					CODE	Better quality of life outcomes e.g. less restrictive and more opportunities.	**100%**	A	B	C	D

COMPARISONS OF FOCUS GROUPS

Question Theme	Leaders 1st Interview	Leaders 2nd Interview
Policy – Communication to the workforce	"Not really sure that it is communicated to the workforce". "Email sent out to managers informing of a policy update". "Manager is meant to discuss policy update in meetings but we often don't have meetings for months due to being short staffed".	"Focus group with staff and service users on the policy". "Safeguarding is consulted about our policy". "Experiences from service users and staff are in the policy" "Policy outlines responsibilities in incident recordings. Everyone has a responsibility".
Discussion & interaction with Leaders & Managers about PBS and experiences	"Staff do become de-motivated and undervalued because the pressure is more but the pay isn't". "Sometimes we just don't know what is wrong so we just have to see the behaviour through. We often feel helpless". "We don't think we understand autism as much as we should so we are left to figure the behaviours out ourselves. We often talk about this as it's a huge problem". "Old cultures not challenged". "When we don't understand something that is not answered for months we start to make judgements". "Professionals don't know what to do sometimes either so we are left to just get on with it". "We don't get adequate de-briefs or only get them when something big happens".	"We know who the lead Director is for PBS". "PBS team involved in discussions with the staff teams" "PBS Lead Director has been to our meetings to discuss experiences". "We feel empowered and consulted". "Our manager has been trained in PBS and has communicated this back to us". "Managers positive about PBS". "Performance targets help keep staff focused and supportive of service users goals".

Constraints of supporting people who challenge	"Directors and Managers are often at a loss with what to do when a service user presents with behaviour". "Small homes create a domino effect with other service users behaviours". "Not enough money for activities. Service users are boarded". "Staffing levels need to be higher". "Commissioners will not fund any more support hours for service users". "Recruitment and getting the right type of person". "Staff get disheartened especially when it comes to person centred approaches as staff are unable to provide the time due to commissioners only funding so many hours. This results in challenging behaviour".	"Environments adapted to meet the needs of the service users through assessments". "Service user s' are active". "Recognition that less staff or negative attitudes is often better to reduce environmental toxins". "Behaviour no longer a constraint".
Values & Attitudes and how they affect practice	"Positive staff moods rub off on service users". "The service users can really pick up on the moods of staff when they are feeling down, tired or negative". "Staff led rather than person centred for service users". "Maintain service users rights". "Lose objectivity when values and attitudes are affected". "Person centred approaches helps spot the early signs/better outcomes for service users".	"Healthy culture and attitudes as staff/managers recognise how toxic environments are created due to attitudes from staff". "More creativity and problem solving". "Culture of reflection and sharing knowledge". "Sense of ownership and morale improvements as a result of PBS". "Focus on the person rather than the behaviour".

	"Use physical intervention as a last resort/more PI". "When new things don't work staff go back to their old ways".	
Current support and challenges	"Compatibility is a daily challenge or incidents are related to incompatibility". "Small group homes can cause behaviours". "Crisis admissions". "Have to pull staff from other services to support an aggressive person. Staff often get hurt because of this". "No breaks and working long hours due to staff sickness". "Focus on behaviour due to becoming stressed/more restrictive practice". "Lack of confident staff".	"Reduction in incidents between service users". "Less sickness/stress due to staff feeling supported". "Less compatibility issues. Service users' are spending time with each other more constructively". "Placements have been maintained".
Training Resources & Improvement Needs	"Its great sitting in a classroom learning about autism but it seems so different when you see it through our own eyes". "Specialised training never really hits the spot or not enough training". "Physical intervention training". "Behaviour specialist nurse. Offers training but not often due to work load". "Challenging behaviour training, which is refreshed every 2 years".	"Contextualised training". "Physical intervention training is only a smaller element as opposed to proactive PBS model". "Recognition that generic autism training has not worked in the past".

	"Specialised training in autism and behaviour that is specific to our service users". "We need incident recording training. We constantly get pulled up for not getting it right but we have never been trained". "We need de-briefing training".	
Assessment, design and implementation of PBS planning	"Staff do not have involvement in assessments/referrals and people are often placed without staff having the time to read assessment profiles". "Very little opportunity to input into PBS plans as the manager tends to write these". "The assessment is normally done before the service user moves in but we've never seen any of that information". "Staff are often in conflict with what managers write in the behaviour plan. We know the service users better so we should be involved in writing the plans".	"Staff fully involved in assessment process and involved in placement decision". "Planned and controlled admissions, which reduced transition and crisis situations". "Staff involved in writing PBS plans".
Understanding of the support planning e.g. why and how	"No time to read and digest plans or policy". "No trigger to behaviour incident". "Strategies don't make sense we they are not used in most part/Often left to judgment call". "Strategies don't say how to implement them/Inconsistencies in implementation". "Strategies inconsistent with autism needs/lack of knowing this".	"Staff/Teams have greater objectivity and understanding". "Understanding autism and communication, e.g. visual cues e.g. in assessments or planning". "PBS plan helps staff to be mindful of gradient approach, rights and restrictions and are related to autism needs". "Clarity in how to implement strategies and reduces inconsistent practice. This reduces incidents as a result". "Increased understanding of the reasons for behaviours and the

	"Right support not given until serious incident occurred".	appropriate strategies to use".
Recording & Reporting – improving clinical practice	"Records don't help to understand the service user better as this is not done. We don't get feedback". "The team doesn't get to discuss incidents. No time to reflect". "Our experiences help us more than the records/we help each other by sharing our experiences". "The paperwork doesn't help us to understand why behaviour has occurred".	"Incident reports/records have improved in standards". "Incident form changed to include the right information for learning". "Reflection on practice section on incident form". "Staff responses to incidents are better and better governance by management/Directors".
Practice standards to improve clinical practice	"How to write behaviour plans". "We would have a better understanding of what to do". "Reduce physical interventions" "Understand autism better". "Understand behaviour better". "Avoid people getting hurt and going into crisis". "Reduce stress in staff/help us to gain confident and reduce stress".	"Recognition from CQC/Professionals on improvements that have been made in practice". "Focus on autism and how this impacts on the service user and consider ways of reducing this. Improvement in clinical practice". "De-briefs happen and they are valued". "Overall team wellbeing improved: confident, high morale, improved reports, recognition of improvements by CQC and social workers". "Reduced behaviour incidents". "Better quality of life outcomes e.g. less restrictive and more opportunities".

Comparison Outcomes From Questionnaires

No.		*1st Questionnaire*					*2nd Questionnaire*				
		Strongly disagree (1)	*Disagree (2)*	*Neutral (3)*	*Agree (4)*	*Strongly Agree (5)*	*Strongly disagree (1)*	*Disagree (2)*	*Neutral (3)*	*Agree (4)*	*Strongly Agree (5)*
Theme	Specific Knowledge										
1	I understand why service users present with behaviours of concern.		35.42%	56.25%	8.33%			10.41%	18.75%	54.17%	16.67%
2	I understand how autism impacts on service users lives.		29.17%	60.42%	10.41%				22.91%	60.42%	16.67%
3	The PBS policy provides me with an understanding of how to support people with autism who may challenge.	12.5%	45.83%	37.5%	4.17%			4.17%	4.17%	79.16%	12.5%
Theme	Attitudes & Experiences										
4	My attitude (and those of my team) positively affects outcomes e.g. quality of life for service users.			20.83%	35.42%	43.75%				29.17%	70.83%
5	I am able to use my experiences positively to improve my practice when supporting people who challenge.		39.58%	27.08%	22.92%	10.42%			12.5%	29.17%	58.33%
6	There is an attitude of reducing restrictive practices.		16.67%	22.91%	50%	10.42%			14.58%	56.25%	29.17%
Theme	Competencies										
7	I am capable of implementing proactive PBS strategies to reduce behaviours of concern from escalating.		27.08%	35.42%	37.5%				12.5%	58.33%	29.17%
8	I am able to safely support a service user and those around them when they present with behaviours of concern.	35.42%	56.25%		8.33%				16.67%	60.42%	22.91%
9	I know how to create an autism specific environment for the service users I support.		16.67%	50%	22.91%	10.42%		4.17%	4.17%	12.5%	79.16%
Theme	Practice Standards										
10	Service Users' behaviour plans provide the necessary information to know how to support them according to their needs.		31.24%	35.42%	29.17%	4.17%			6.25%	31.24%	62.51%
11	I understand what is expected of me to ensure service users' rights are maintained, especially when they present with behaviours of concern.			31.25%	64.58%	4.17%			4.17%	35.42%	60.41%

12	Our current practice standards provide me with confidence that I am providing good support.	10.42%	37.5%	41.66%	10.42%				12.5%	29.17%	58.33%
13	Current training for my service is appropriate for the people I support.	4.17%	12.5%	45.83%	37.5%				6.25%	62.51%	31.24%
Theme	Service Outcomes										
14	There is a focus on the person and not their behaviour.		4.17%	31.25%	64.58%					29.17%	70.83%
15	Restrictive practice, e.g. restraint is a daily occurrence in the service.		8.33%	35.42%	56.25%		35.42%	60.41%	4.17%		
16	Service Users' are not restricted in their skills and independence as a result of their behaviours of concern.	64.58%	31.25%	4.17%					16.67%	22.91%	60.42%
Theme	Monitoring practice performance										
17	Incident recording and reporting is clear and objective.	10.42%	41.66%	37.5%	10.42%					91.67%	8.33%
18	Incident reporting leads to more proactive management behaviour.	10.41%	29.17%	60.42%						95.83%	4.17%
19	I am offered a de-brief after an incident.	29.17%	58.33%	12.5%					6.25%	93.75	
20	The monitoring systems that are currently in place help us to reflect and learn how to improve our clinical practice.	8.33%	35.42%	56.25%					4.17%	16.67%	79.16%