Facilitating an enabling relationship in Active Support:

evaluating the use of video informed reflective practice with staff

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Declaration

I declare that the research reported is my own, and not submitted for any other academic award.

Note to Examiner

Please note that the topic of the systematic literature review does not link with the main research report. I would like to explain the rationale for this decision. A systematic literature review had been completed in the field of active support shortly before I embarked on my research study, and it was deemed inappropriate to replicate this. Following discussion with my supervisor, a decision was made that it was more appropriate to engage in a systematic literature review that was relevant to my current work setting, and also an area in which there was an identified gap in the literature.

Thesis Abstract

This portfolio contains three pieces of research, in the following areas:

Research Report: this study evaluated a revised package of active support (AS), which modified standard AS training to include a video informed reflective practice. In addition to standard methods for evaluating AS, a new observational tool was piloted to code the presence of positive and negative interactions between staff and service users. Results showed moderate effect sizes for service user engagement, staff assistance, and both positive and negative interactions following the training.

Systematic Literature Review: the aim of this review was to describe and synthesise the literature examining the outcome of mindfulness based therapies on the psychological functioning of people with Autistic Spectrum Disorder. Eight studies were identified for inclusion. Overall results showed reductions in a range of psychological symptoms. The quality of included studies was mostly weak, and methodological limitations are discussed.

Service Evaluation: this project aimed to evaluate the effects of a mindfulness intervention on family caregivers of adults with learning disabilities or physical/mental health problems. Quantitative measures at pre, post, and two month follow-up, and qualitative analysis of a focus group were used to evaluate the programme. No significant change was found on quantitative measures of well-being or carer quality of life, however the qualitative evaluation revealed interesting themes about how participants experienced a mindfulness based intervention.

This is followed by a critical appraisal of the research report.

Acknowledgements

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Section 1.0: The Research Report

Facilitating an enabling relationship in Active Support:

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Abstract

Active Support (AS) should promote positive relationships between staff and service users, in addition to increasing engagement in meaningful activities. The current study evaluated a revised package of AS, which included standard AS training and an additional relationship building component involving video informed reflective practice. The training package was implemented in four residential learning disability homes, using a multiple baseline across environments design. Training consisted of a one day workshop, and follow-up coaching. Coaching used a video reflective format, to focus on elements of relationship building in addition to standard AS components. Momentary time sampling was used to measure engagement levels. A new observational tool was piloted to code the presence of positive and negative interactions by staff. Results showed moderate effect sizes for service user engagement, staff assistance, and both positive and negative interactions following the training. The implication of these results is discussed, both for the local service context, and their wider contribution to the AS literature.

1.1 Introduction

AS is a model of care that focuses on helping staff in community homes to deliver practical support to people with learning disabilities. The support focuses primarily on helping residents to engage meaningfully in activities that make up 'everyday life'. The original approach was developed more than 25 years ago, and today it has become one of the best evidenced models of care in the field of learning disabilities (Mansell & Beadle-Brown, 2012). The fundamental components of AS were first developed and evaluated in demonstration projects in the UK during the 1980s, at a time when England's first community homes for people with learning disabilities were being piloted (Totsika, Toogood & Hastings, 2008). The philosophical drive for community care arose out of the normalisation movement, and the recognition that institutions were often barren, un-stimulating and lacking in meaningful and varied activities for the residents who lived there. The normalisation movement promoted the idea that people with learning disabilities should live in ordinary places, and do ordinary things with ordinary people. With the move to community based homes there was an expectation that quality of care and access to 'normal' patterns of everyday life would improve (Ashman, Beadle-Brown, & Mansell, 2010).

AS further operationalised this philosophy, by focusing on the concept of engagement and the extent to which a person has opportunities to engage in purposeful and meaningful interactions with both the social and material environment (Totsika et al., 2008). This created a shift in focus away from people's disabilities and what they couldn't do, to what they could do and had the potential to learn to do. This focus is reflected in the approach that AS takes to staff training. Staff are encouraged to see their role as support planners, enablers and teachers. They are taught systematic ways of *planning* and organizing the residential environment to promote active participation for

residents. They *enable* by providing support and assistance on a moment by moment basis, and bridging skill gaps where necessary. They *teach* by reinforcing behaviour associated with active participation, and using teaching programmes to help establish new behaviour where necessary (Totsika et al., 2008).

1.1.1 Structural Components of AS

Over the years, the structural components of AS have been developed and refined, and a variety of teaching resources have been published. Jones et al. (1996) published a series of booklets, and more recently Mansell and colleagues have developed a person centered AS training package to better reflect the core principles of person centered planning (Mansell, Beadle-Brown, Ashman, & Ockenden, 2005). This resource has also encouraged services to shift their focus away from heavy use of paper-based planning and move towards encouraging managers to model and monitor the components of AS through a direct hands-on, shop-floor approach.

Broadly speaking, while there have been some refinements to AS since its conception, the fundamental components have remained the same. These can be captured within four main areas. First, staff members take a proactive approach to planning activities in advance (Mansell et al., 2005). Most households have regular routines and systems in place to ensure that individual people's needs are met, and the activities that they want to do are completed. In AS, a similar system is developed to map out and plan everyday activities and routines (Totsika et al., 2008). Second, staff organize the support that they provide. This involves a clear allocation of staff to duties and residents, and clear communication about division of responsibility. Third, staff use an 'enabling' style of interaction to promote residents engagement in activities. This involves staff providing graded levels of assistance to ensure success in a task, with help progressing from explicit verbal instruction, to gestural physical prompts, to

demonstration, to physical guidance. Staff are also encouraged to find the 'doable' steps from within a complex task and to be opportunistic about looking for the potential within all 'moments'. Finally, staff monitor the opportunities that they provide and use procedures to monitor and reflect on their own practice in order to improve the quality of care that they provide (Mansell et al., 2005).

1.1.2 Effectiveness of AS

Jones et al. (1999) undertook the first experimental evaluation of AS, by examining its effects in five group homes in Wales. Staff and resident behaviour was observed by researchers and a momentary time sampling procedure was used to record resident's engagement in activity and the attention they received from staff. The AS training intervention was staggered across the five houses at monthly intervals, with 10 data points at baseline and post-baseline, and two at follow-up (6 months, and 8-12 months after training). The results demonstrated that following AS training, residents received significantly more assistance from staff and were significantly more engaged in meaningful activity. Resident engagement was shown to increase from 33% at baseline to 53% after AS intervention and 57% at follow-up. These results demonstrated proportional increases of 61% and 73% respectively. Importantly, these improvements were shown to occur without any additional staff, suggesting that AS resulted in a more effective use of staff resources (Jones et al., 2001). Other studies have gone on to replicate these findings and there is now a comprehensive literature to show that AS increases residents' engagement in activities of daily living, and improves the amount and type of support that staff provide (Bradshaw et al., 2004; Jones et al., 2001; Mansell, Elliot, Beadle-Brown, Ashman & Macdonald, 2002; Smith, Felce, Lowe & Jones, 2002; Stancliffe, Haarman, Toogood, & McVilly, 2007).

There is further evidence that AS improves not just the *quantity* of staff attention, but also the *quality*. People with severe learning disabilities have been found to respond best to non-verbal instructions (Jones et al., 2001). Interestingly though, most staff interaction takes the form of verbal conversation, which has been shown to do little to facilitate engagement in activity (Felce & Perry, 1995; Hewson & Walker, 1992). AS emphasises training staff to provide more effective assistance, by tailoring their style of support to the needs of residents. Staff are encouraged to use gestural or physical prompting, demonstration, and guidance, and to avoid repeating verbal instructions when they are ineffective (Jones et al., 2001). Smith et al. (2002) showed that staff trained in AS became more efficient at matching support strategies to resident need, particularly their use of non-verbal assistance.

AS has been shown to be particularly helpful for people with more severe disabilities, and associated lower levels of independence and adaptive functioning. Generally speaking, the more disabled residents are, the less time they spend occupied in meaningful activity (Jones et al., 2001). It is these residents in particular who rely on staff to play a central role in mediating their access to opportunities and activities (Mansell, Beadle-Brown, McDonald & Ashman, 2003). However, a number of studies have found that staff actually provide more attention and assistance to residents who are more behaviourally able. Jones et al. (1999) found that there was a correlation between scores on a measure of adaptive functioning (the Adaptive Behaviour Scale) and amount of staff attention, with staff giving more able residents more support prior to any AS training. A similar finding was reported in studies by Jones et al. (2001) and Smith et al. (2002). AS training has been shown to alter this trend, so that following the training less able residents receive at least as much staff attention and assistance as more able residents (Jones et al, 2001).

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1.1.3 Staffing Factors

The findings about adaptive functioning are important because they suggest that there are particular characteristics of residents that influence the impact and effectiveness of AS. Other lines of enquiry have focused on features such as staff characteristics, setting variables, and training approaches to help understand more about the conditions under which AS is likely to be of greatest benefit. Managerial commitment has been shown to be an important component in the successful implementation and maintenance of AS. Following AS training, it is the home managers who assume responsibility for this role. Some studies have shown poor and inconsistent outcomes when home managers were not involved in onsite training and lacked an understanding of the aims of AS (Bradshaw et al., 2004). Staff themselves report that a lack of 'hands on' management is one of the factors that they find most challenging in their endeavours to support residents effectively (Mansell, Beadle-Brown, Whelton, Beckett & Hutchinson, 2008). Mansell et al. (2005) highlighted that practice leadership by front line managers appears to be an important element for shaping staff skills and maintaining staff motivation.

A number of studies have examined staffing characteristics and variables that influence the process of AS. While having adequate staffing is generally recognised as important, several studies have shown little relationship between staff to resident ratio, and the extent of interaction that staff and residents have (Felce, Lowe, & Jones, 2002; Hatton, Emerson, Robertson, Henderson & Cooper, 1996). In terms of training approaches, one clear finding has emerged about the components that contribute to the effective 'uptake' of AS approaches in community homes. AS training involves a combination of both 'workshop' classroom teaching sessions, and follow-up on-site coaching, in which trainers work with individual staff and residents to teach AS skills in

the home environment. Several studies have shown that the improvements generally associated with AS do not occur when the onsite 'coaching' component is missing. (Jones et al., 2001; Smith et al., 2002).

1.1.4 The Role of Relationships and Rapport

The AS model has gone a long way to addressing quality of life issues for residents living in community homes. It has a strong focus on developing and promoting styles of staff support that help residents engage more meaningfully in activities of daily life. Being busy is clearly an important part of leading a 'good life'. In recent years, there has been increasing recognition that while doing meaningful activities is important for a good quality of life, it is not the only component. The social relationships that people develop clearly have an important impact on their emotional and mental well-being, and this factor tended to be overlooked in the early AS literature. People with learning disabilities often have limited opportunities to develop social relationships with their peers, and many in residential services have limited or no contact with family members. For this reason, the relationship that they develop with staff is often their main source of social contact.

While the quality of the relationship between people with learning disabilities and their caregivers is increasingly being recognized as an important variable in the learning disability literature, there has been surprisingly little focus on how to quantify or improve it. In recent years the concept of 'rapport' has begun to be examined within the context of the positive behavioural support (PBS) model. There is some evidence that problem behavior occurs more often in the presence of staff that are 'non-preferred' than those that are 'preferred', especially when demands are made of the service user (Carr et al., 1994; Kemp & Carr, 1995). Other studies have also found that service users showed higher levels of smiling and laughing, and lower levels of crying and yelling

when they had positive interactions with staff members (Favell, Realon, & Sutton, 1996).

McLaughlin and Carr (2005) conceptualized rapport as a potential setting event in the PBS model, hypothesizing that good rapport might act to alleviate the aversiveness of task demands, and subsequently reduce the likelihood of escape-motivated problem behavior. They conducted two studies to further assess the effects of rapport on problem behavior. In the first study rapport was operationally defined, and 'good' and 'bad' rapport dyads were identified. This was based on a multi-modal assessment method that included staff interview, subjective rating scales, and direct observation. They then assessed the effects of rapport on participants' response to demands, comparing 'good' and 'poor' rapport dyads in demand versus no demand conditions. A functional analysis of each participant's problem behavior was conducted. Results showed that when a demand was presented and rapport was poor, levels of problem behavior were high, and when rapport was good, levels of problem behavior were low. The authors highlighted the potential usefulness of a multi-modal approach to assessing rapport, concluding that service users' judgments and choices about staff members, and peer ratings are particularly helpful methods for establishing levels of rapport within staff: service user relationships.

In a second study, an intervention package designed to improve rapport was evaluated. The aim of this study was to give 'poor rapport' staff members the opportunity to learn strategies to build and enhance rapport. The staff were trained in a number of strategies designed to improve their responsiveness to service user's communications. Following this intervention, staff members who were previously assessed to have 'poor rapport' showed an improvement in their rapport; they were chosen more often as 'preferred staff' by service users, and their peer ratings of rapport

improved. When rapport improved, so too did service user's compliance with and completion of tasks, and there was a decrease in problem behavior. Interestingly, the staff members themselves also described improved levels of satisfaction in their relationships with the service users that they had received rapport training with. What these studies seem to suggest is that there is something about the quality of the relationship that is important from the service user's point of view, and that has an impact on how willing they are to engage in more difficult activities. McLaughlin & Carr (2005) highlighted the usefulness of investigating the role of rapport in other well established interventions, such as AS.

More recently, Mansell and Beadle-Brown (2012) have explored the idea of an 'enabling relationship' in more detail, recognising that the relationship that staff have with service users is pivotal to implementing AS well, and looking at what it is about the relationship that is important. They identified three elements that they see as key to facilitating enabling relationships. The first is the values and attitudes that staff bring to the job. This relates to the extent to which staff believe that people with learning disabilities can, and should have opportunities to participate in meaningful activities, and a willingness to be involved in this process. The second element is that of matching staff and service users to maximise opportunities for positive rapport, not just in terms of similar interests, but also in terms of a staff member's ability to empathise and create emotional connections with the person that they support. The third key element is ensuring that staff have the ability and the support to critically reflect on the relationships that they develop with service users. By highlighting the importance of the reflective process, there is a recognition that the enabling relationship is not necessarily a process that happens spontaneously, but rather one that requires a commitment to ongoing reflection and adjustment. Mansell and Beadle-Brown (2012) describe this as

potentially a more demanding and creative role than just being focused on the activities and tasks of AS.

Baker and Shephard (2010) were interested in developing a procedure within AS, that helped staff to critically reflect on their own practice, with a particular emphasis on building positive relationships with service users during the AS process. They developed a revised package, which combined a standard AS training package with a video reflective procedure. This component occurred during the staff coaching phase, when trainer and staff member videotaped interactions of the staff member and service user, and used this to reflect together on aspects of the staff member's performance. They used momentary time sampling to do a preliminary evaluation of the intervention with seven residents, and found positive results that were consistent with standard AS studies. Following the intervention, service users' engagement in meaningful activity increased from 54% to 70%. Staff also spent more time engaging residents in meaningful activities, with total staff attention increasing from 34% to 46%. The relationship building component of the intervention was not assessed.

1.1.5 Measuring the Quality of Interaction between Staff and Service Users

In the field of dementia services, more systematic approaches have been developed to quantify the characteristics of both positive and negative social interactional style between caregivers and service users. Dementia Care Mapping (DCM) is an evaluation tool that was developed by Kitwood and Bredin (1992). It focuses on measuring quality of care from the perspective of the recipient. The tool has prescriptive coding frames and clearly defined rules for observations, and places particular emphasis on aspects of social interactions (Persaud & Jaycock, 2001). DCM uses two coding frames, which address both positive and negative aspects of caregiving practice. 17 dichotomous categories describe the style of support provided, with

particular emphasis on aspects of the social and emotional interaction. During observations, interactions are rated on the categories using a four point scale. This information is then analysed and fed back to staff teams with the aim of facilitating quality improvement in care practice. There is a growing literature base regarding its use in dementia services, demonstrating changes in quality of care over time (Jaycock, Persaud, & Johnson, 2006). To date there has been limited application of the tool in learning disability settings (Jaycock et al., 2006; Persaud & Jaycock, 2001). However interest in its potential application is growing, with a recognition that dementia care and learning disability services face similar challenges in promoting positive relationships between staff and service users.

More recently, a new observational tool called the Positive Interactions Checklist has been piloted in a learning disability setting (Vanono, Dotson, & Huizen, 2013). It focuses on operationalising 'positive interactions' between staff and service users. The tool consists of eight categories of positive interactions that have been derived from the work of Mansell and Beadle-Brown (2005), and Carr, Smith, Giacin, Whelan and Pancari (2003). It was used in a recent study to evaluate the effects of 'positive interaction training' on staff members working in a day service setting (Vanano et al., 2013). The tool holds some similarities to the DCM tool developed for use in dementia care services. However, unlike the DCM measure it does not have any capacity to evaluate 'negative interactions' that might occur between staff and service users. Arguably, a modified version of the positive interactions checklist, containing categories for recording 'negative interactions' could provide a useful, more comprehensive way of assessing the role of relationship building in AS, and build on the preliminary investigations that Baker and Shephard (2010) began.

1.1.6 Aims of Current Study

On the basis of the literature that has been described, the aims of the current study were:

1. To pilot a revised version of AS, combining standard components with a video informed reflective practice, used during the coaching phase to promote staff's ability to reflect critically on their practice.

2. To measure the effects of the training package on the quality of the relationship between staff and service users, using a modified version of the Positive Interactions Checklist (Vanono et al., 2013).

3. To measure the effects of the training package on service users' level of engagement in meaningful activities.

4. To measure the effects of the training package on staff assistance.

It was hypothesized that positive interactions between staff and service users would increase, and negative interactions would decrease following the implementation of the AS training package. It was also hypothesized that following AS training service user engagement levels in meaningful activities and staff assistance would increase.

1.2 Method

1.2.1 Experimental Design

A multiple baseline across environments design was used, with intervention staggered across four environments at approximately one month intervals. In this design the independent variable was the implementation of the AS training package. The dependent variables were 1) service user engagement levels, 2) staff assistance levels, and 3) positive and negative interactions between staff and service users. This design was considered to be more robust than a pre-post intervention design, because it would indicate more clearly whether any changes to the dependent variables co-occurred with

manipulation to the independent variable. Practical aspects of the service also lent itself well to this design. It enabled trainers/coaches to focus on one house at a time, thus maximizing the intensity of input into one service, before moving on to the next.

The multiple baseline design demonstrates the effects of an intervention by intervening on several baselines at different points in time (Kazdin, 2011). Effect sizes were estimated using the Tau U statistic. Tau U combines non-overlap between baseline and intervention phases with considerations of trend within the intervention phase and optional control of undesirable baseline trend (Parker, Vannest, Davis, & Sauber, 2011). Interpretation of effect sizes were based on the guidelines reported by Ferguson (2009).

1.2.2 Participants and Settings

The residents of four staff community houses participated in the study. The houses were selected with the aim of obtaining a representation of people with severe and moderate rather than mild learning disabilities. A total of 25 people lived in the houses, five in house (a), six in house (b), eight in house (c), and six in house (d). Twelve residents were male, and 13 were female. At baseline, the ages of the residents ranged from 22-69 years, with a mean age of 45. In house (a) the mean age was 37, with 4 females and 1 male. In house (b) the mean age was 40, with 3 females and 3 males. In house (c) the mean age was 56, with 4 females and 4 males. In house (d) the mean age was 50, was 2 females and 4 males.

In addition to age and gender, information on each participant's adaptive behavior, challenging behavior, and social impairment was collected by completing the following assessment measures with staff who knew the service user well. These measures were selected because they are used frequently in other AS research studies, to provide a common framework for understanding the demographic characteristics of the

populations described. The advantage of selecting these measures for the current study was firstly, because they are shown to demonstrate good reliability and validity properties (Harrison & Oakland, 2003; Holmes, Shah, & Wing, 1982; Rojahn et al., 2013), and secondly because it allowed direct comparisons about demographic characteristics to be made with existing studies.

(a) Level of adaptive functioning was measured by the Adaptive Behaviour Assessment System (ABAS–II; Harrison & Oakland, 2003). This is a measure of adaptive functioning that is normed on the general population, and has a mean of 100 and a standard deviation of 15. Scores below 70 are generally considered to be indicative of a Learning Disability (British Psychological Society, 2015). The mean ABAS-II score overall was 45, (range = 40-65). The individual houses had mean scores of (a) 40, (b) 40, (c) 53, and (d) 45, indicating that participants were primarily within the range of moderate to severe learning disability (British Psychological Society, 2015).

(b) The Aberrant Behaviour Checklist (ABC; Aman & Singh, 1986) was used to provide a measure of challenging behavior. 58 behaviours are rated on a four point scale according to overall level of severity. The behaviours are categorized into five areas: Irritability, Lethargy, Stereotypy, Hyperactivity and Inappropriate Speech. The mean scores for the houses were as follows: house (a) 55, house (b) 15, house (c) 23, and house (d) 9. The overall mean score on the ABC was 23 (range = 0-134). This was comparable to the mean score reported by Beadle-Brown, Hutchinson and Whelton (2012) during baseline, but lower than the mean scores reported by Jones et al. (2001) and Felce et al. (2002) of 37 and 39 respectively.

(c) The Quality of Social Impairment question from the Disability Assessment

Schedule (Holmes et al., 1982) was used to assess the presence of the triad of

social impairments characteristic of autistic spectrum disorder. Five participants

were identified to have the triad of social impairments on this measure, three in

house (b), and two in house (c).

A total of 54 staff from the four houses completed the AS training package. Two

managers had responsibility for managing the four houses.

1.2.3 Ethical Consideration

Ethical approval to undertake the study was obtained from the local Health and

Social Services Department Ethics Committee (Appendix A). Consent to participate in

the study was sought from all clients who were deemed (by service managers) to have

the capacity to provide it. Four service users were able to provide informed consent,

using an accessible information sheet (Appendix B). In the UK, the Mental Capacity

Act (Department of Health, 2005) provides the legal requirements for conducting

research with people who lack the capacity to consent. While this project was conducted

in a location where the Mental Capacity Act (MCA) does not apply, in the absence of a

local legislative framework the principles of the MCA were followed as "best practice".

Wherever possible, appropriate family members were contacted, provided with

information about the project, and asked for their advice about whether the identified

service user should take part. An information letter was provided as part of this process

(Appendix C). Where it was not possible to consult with appropriate family members, a

professional identified to have a good relationship with the service user was consulted.

All family members and staff who were consulted identified that it was appropriate for

the person in question to take part in the project. In accordance with the principles of the

MCA, it was agreed that if any service users displayed any behaviours that could be

interpreted as 'non consent', collection of their data would cease. No service users were observed to behave in ways that suggested non consent.

1.2.4 Intervention

Managers of the houses were involved in the planning stages of the project to encourage successful implementation. AS training consisted of a one day classroom based training session. The materials for the workshop were based on a training package developed by Mansell et al. (2005)**.** The training workshop also included video footage of service users (from the relevant house) that had been collected by trainers prior to the workshop. The rationale for including video footage was two-fold: to make the training as relevant as possible to the individual houses, and to introduce the reflective video feedback process, that formed the basis of the follow-up coaching sessions. The workshop training was delivered approximately a month apart for each of the four houses.

Following the training workshop, each individual staff member received a two hour follow-up coaching session. These sessions took place within a one month period following the workshop training. The coaching was provided by one of three AS trainers (clinical psychologist, behaviour specialist, or assistant behaviour specialist). All of the trainers had previously undertaken a two day workshop in delivering AS training, by a UK based consultant.

Coaching Sessions

Coaching sessions took place in the house environment. A coaching session consisted of coach and staff member identifying an appropriate activity to support a service user with, and then carrying out the activity. The coach videoed the activity, and the coach and staff member then reviewed the video together, using the video reflection checklist **(**Appendix D**)** as a prompt. The staff member then identified one goal for

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improving their style of support, and completed another videoed activity, focusing on the identified goal. The video was reviewed again by coach and staff member, and general goals for future practice were discussed. The staff member received a completed copy of the video reflection checklist for future reference. The coaching process was based on a facilitative style, whereby the coach facilitated the staff member to reflect critically on their own practice, rather than offering 'expert' opinion or 'teaching' about the process. The coaching phase lasted for approximately one month in each house. During this time, coaches also worked more generally with the staff team, to encourage the development of shift planners, and other organizational aspects of AS. Following the coaching phase, the house managers and senior staff assumed responsibility for implementing and maintaining AS.

1.2.5 Data Collection

Data was collected in two hourly sessions. Data was collected across three different time periods, including a morning, early afternoon, and late afternoon session. The amount of data collected during each time period was equal across houses, to ensure consistency across environments. Data collection sessions occurred over a 10 month period, with approximately two observation sessions per week in each house.

Observations of service user and staff activity:

Momentary time sampling with one minute intervals was used to observe service user and staff activity. Observers rotated evenly around service users during the observation period. Six staff and six service user behaviours were measured according to the definitions developed by Jones et al. (1999), (Appendix E**).**

Observations of staff: service user interactions:

Using the DCM tool (Kitwood & Bredin, 1992) and the Positive Interactions Checklist (Vanono et al, 2013) as a guide, 14 dichotomous categories were developed,

to measure aspects of staff's interactional style with service users. The categories

measured the following seven dimensions of interactional style: attention, verbal

warmth, humour, non-verbal warmth, choice, facilitation, and management of

challenging behaviour based on the PBS model. There was a dichotomous positive and

negative category for each dimension (Appendix F).

At five minute intervals an observer coded the quality of the staff's interaction

with service users, on each of the seven dimensions. A choice of three ratings was made

for each of the seven dimensions: positive interaction, negative interaction, or neutral

(neither clearly one nor the other). The rating for each dimension was made on the basis

of interactions observed over a one minute period preceding each fifth minute of the

observation period. When a coding of inattention was made, the remaining six

dimensions were not coded for that minute.

1.2.6 Inter Observer Agreement (IOA)

One main observer trained a team of five observers to conduct the observations.

The main observer was also involved in other aspects of the project, including staff

coaching, and data analysis. Each observer completed a training session in one of the

houses, prior to commencing observations. The training session continued until there

was 80% IOA (with the main observer) for a continuous period of at least 20 minutes.

IOA for the direct observations was then assessed by the presence of the main observer,

in 11 two hour sessions. Inter-observer agreement was obtained for 13% of the total data

collected. Cohen's kappa was used to calculate level of IOA. This provides an estimate

of agreement between two independent observers once levels of chance agreement have

been taken into account. Kappa values of 0.94 were calculated for staff behavior codes

(Jones et al., 1999), 0.92 for service user behavior codes (Jones et al., 1999), and 0.74

for interaction checklist categories. Suen and Ary (cited in Jones et al., 1999) suggest that a kappa value of 0.6 or higher is acceptable for observational research.

1.3 Results

1.3.1 Service User Engagement Levels

Four service user behaviour codes (social engagement, non-social engagement-domestic, non-social engagement-personal, and non-social engagement-other) were added together to give a measure of service user engagement level (Jones et al, 1999). Figure 1 shows the percentage of time that service users were engaged in meaningful activity before and after the introduction of AS training. Service (a) saw a rise in percentage engagement from 52% to 65%, service (b) 39% to 60%, service (c) 71% to 73% & service (d) 48% to 69% with the combined services engagement rising from 55% to 70%.

A visual analysis of the data indicated that there were high levels of variability within the data, particularly in houses (a) and (b). There was also evidence of baseline trend in house (b), and this was corrected for, prior to the calculation of effect size. Tau U effect size estimates indicated that the intervention had a moderate effect on service user engagement with a range of strong to minimal across services (Table 1).
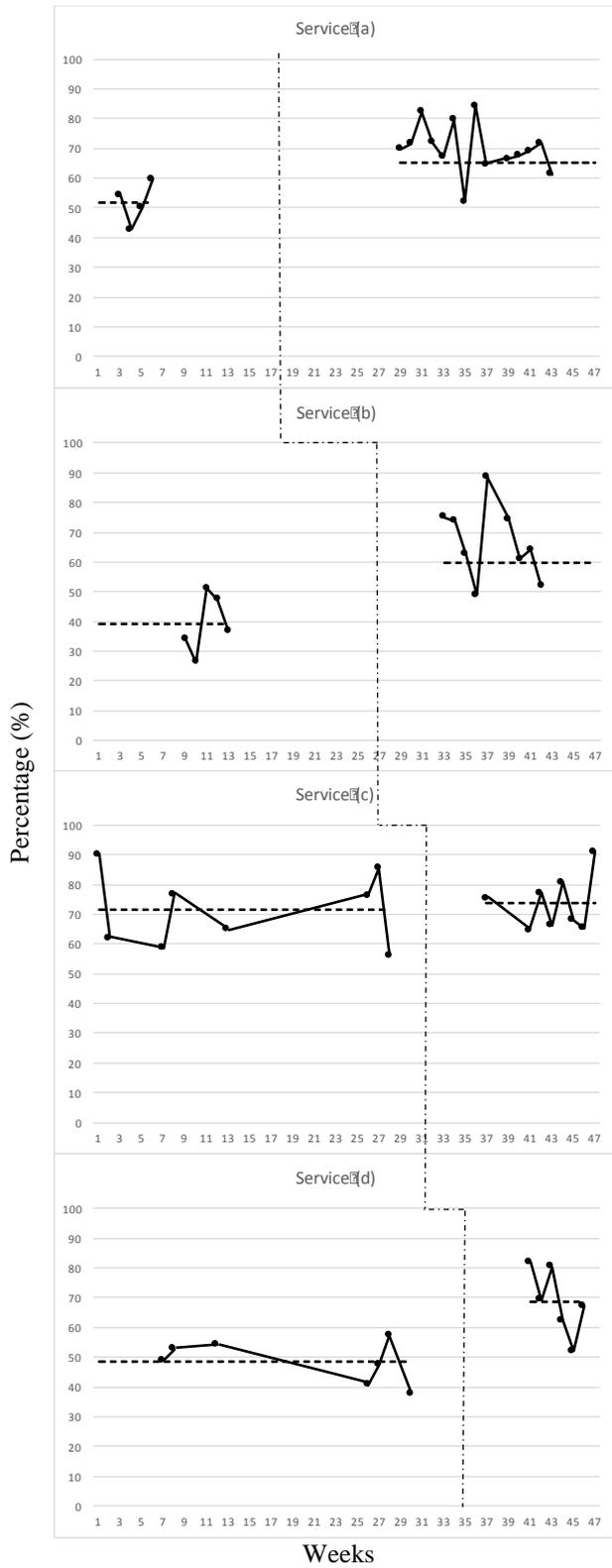
Figure 1. Percentage engagement scores across service environments

1.3.2 Staff Assistance

The percentage of time that staff provided assistance (the help staff give people to be engaged in meaningful activities) are illustrated in Figure 2. Service (a) saw a rise from 20% to 26%, service (b) 13% to 35%, service (c) 15% to 16% & service (d) 7% to 16% with the combined services assistance rising from 13% to 24%. In house (a) there was evidence of baseline trend, and this was corrected for prior to the calculation of effect size. While the remaining houses showed relatively stable baselines, there was considerable variability in the intervention data, particularly in house (b). Tau U effect size estimates indicated that the intervention had a moderate effect on staff assistance with a range of strong to minimal across services (Table 1).
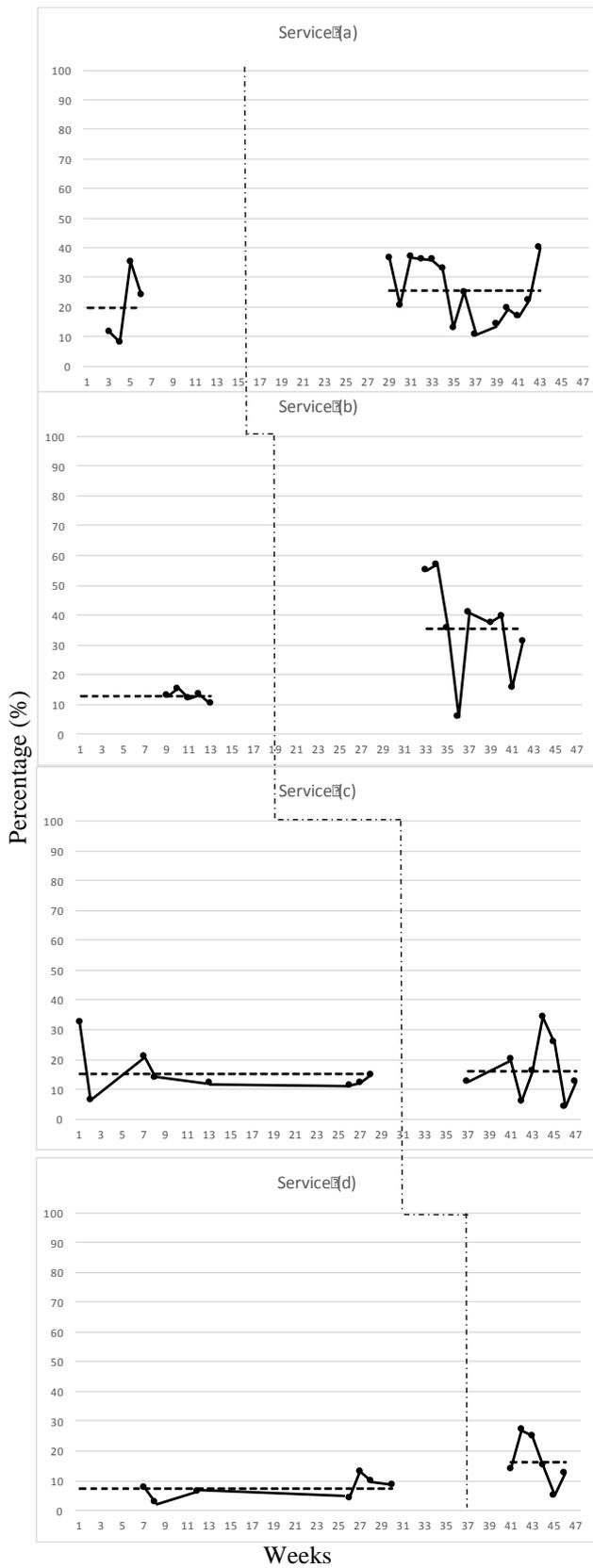
Figure 2. Percentage of staff assistance scores across service environments

1.3.3 Staff: Service User Interaction

The percentage of positive and negative interactions was calculated for each house, before and after the introduction of AS training. Percentage of positive interactions was calculated using the equation:

$$\frac{\text{Total number of positive interactions}}{\text{Total number of positive + negative interactions}} \times 100$$

Percentage of negative interactions was calculated in the same way. Positive interactions increased in service (a) from 29% to 36%, service (b) 32% to 40%, service (c) 26% to 31% & service (d) 13% to 40%. There was an overall service increase from 22% to 37%. Negative interactions decreased in service (a) from 28% to 17%, service (b) from 38% to 12%, service (c) 37% to 24% and service (d) 44% to 19%. There was an overall service decrease of 43% to 18%. Again, there was evidence of considerable variability within the data, and baseline trend in house (a), which was corrected for prior to the calculation of effect size. Tau U effect size estimates indicated that the intervention had a moderate effect on both positive and negative interactions with a range of strong to minimal across services (Table 1)
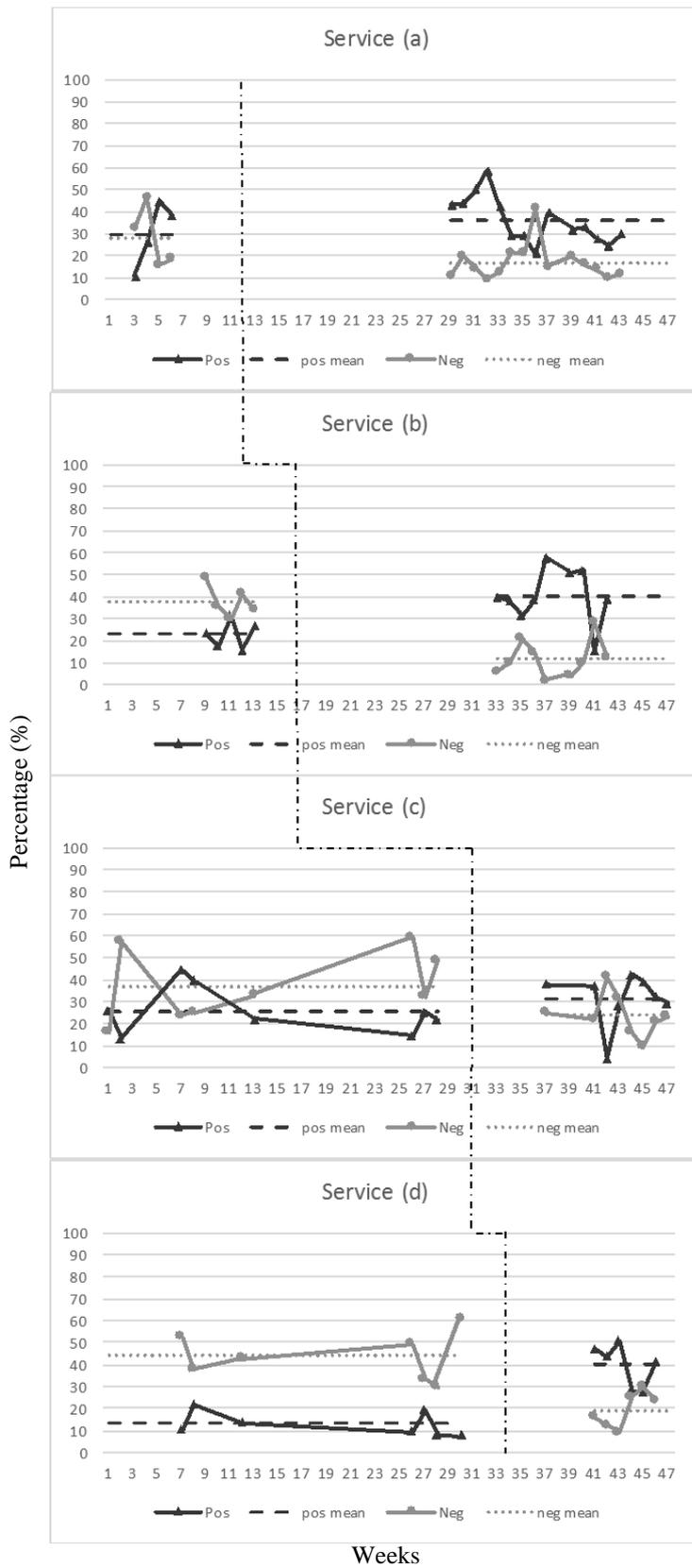
Figure 3. Percentage positive and negative interactions across service environments

Table 1.

Weighted Tau-U effect sizes for engagement in meaningful activity. staff assistance. and positive and negative interactions

	Tau	**p-value**	**90%confidence**	**Degree of effect**
Engagement				
Service (a)	0.93	0.006	0.38 to 1.48	Strong
*Service (b)	0.91	0.006	0.37 to 1.46	Strong
Service (c)	0.22	0.46	-0.27 to 0.71	Minimum
Service (d)	0.86	0.01	0.31 to 1.41	Strong
Combined data	0.71	0.0001	0.39 to 1.03	Moderate
Staff Assistance				
*Service (a)	0.36	0.29	-0.2 to 0.91	Minimum
Service (b)	0.78	0.02	0.23 to 1.33	Moderate
Service (c)	0.09	0.75	-0.4 to 0.58	Nil
Service (d)	0.71	0.03	0.17 to 1.26	Moderate
Combined data	0.61	0.001	0.22 to 0.75	Moderate
Positive Interactions				
*Service (a)	0.14	0.67	-0.4 to0.70	Nil
Service (b)	0.78	0.02	0.23 to 1.33	Moderate
Service (c)	0.34	0.25	-0.15 to 0.83	Minimum
Service (d)	1	0.003	0.45 to 1.55	Strong
Combined data	0.56	0.0006	0.24 to 0.88	Moderate
Negative Interactions				
*Service (a)	-0.53	0.11	-1.09 to 0.02	Moderate
Service (b)	-1	0.003	- 1.55 to -0.45	Strong
Service (c)	-0.59	0.05	-1.08 to -0.1	Moderate
Service (d)	-0.98	0.003	-1.53 to -0.42	Strong
Combined data	-0.77	0.0001	-1.09 to -0.45	Moderate

*corrected for baseline trend

The percentage of change across positive and negative interactions was calculated for each of the seven dimensions of the Interaction Checklist (IC). Figures 4 and 5 show the percentage of positive and negative interactions before and after training, across individual dimensions of the IC.

Percentage of positive interactions between staff and service user
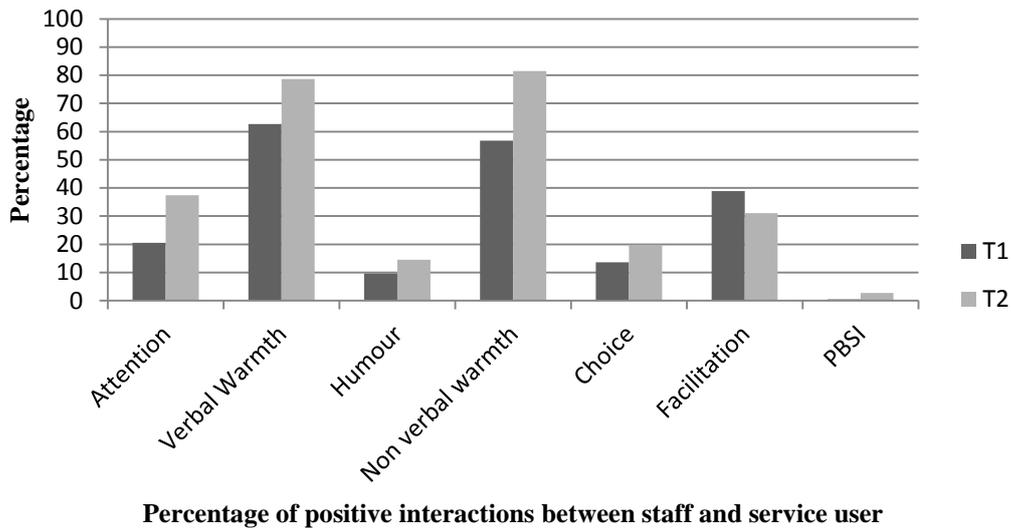
Figure 4. Percentage of positive interactions before (T1) and after training (T2), across individual dimensions of the IC.

Percentage of negative interactions between staff and service user
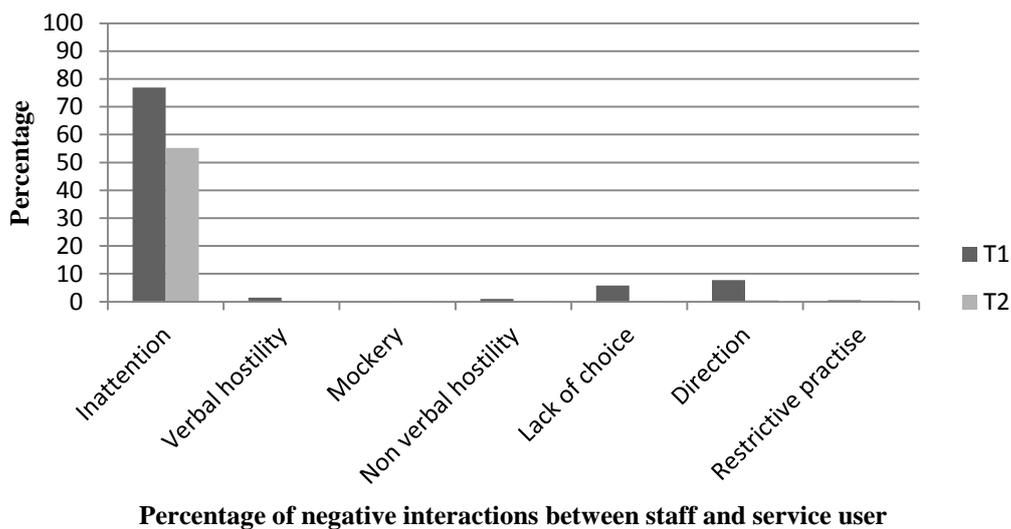
Figure 5. Percentage of negative interactions before (T1) and after training (T2), across individual dimensions of the IC.

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1.4 Discussion

1.4.1 Summary of findings

The aim of the current study was to pilot a revised version of AS, which combined standard components with a video informed reflective practice, used during the coaching phase to promote staff's ability to reflect critically on their practice. The study also aimed to measure the effects of the training package on the quality of the relationship between staff and service users, using a set of behavioural codes which focused on positive and negative aspects of their interactional style. Finally, the study aimed to measure the effects of the training package on service users' level of engagement in meaningful activities and staff assistance, as consistent with other studies of AS.

A multiple baseline across environments design was used, with AS training staggered across four community learning disability homes. The dependent variables used to measure the effect of the training were 1) service user engagement levels, 2) staff assistance levels, and 3) positive and negative interactions between staff and service users. 25 service users with moderate to severe learning disabilities were included in the study. A total of 54 staff participated in the training, which consisted of a one day workshop, and a follow-up video informed reflective coaching session in the home environment.

Observations of service user and staff activity were made using momentary time sampling at one minute intervals. Ratings of staff and service user interaction were made at five minute intervals. The quality of the interaction was rated as positive or negative across seven dimensions: attention, verbal warmth, humour, non-verbal warmth, choice, facilitation, and style in which challenging behaviour was managed. Overall, the results of the study showed that there were moderate effect sizes for service

user engagement, staff assistance and positive and negative interactions between staff and service users.

Looking first at service user engagement, the results indicated that all four houses demonstrated an increase in service user engagement level following training, with strong effect sizes in three of the four services. House (c) appeared to show a ceiling effect, with high baseline engagement (74%) before intervention commenced. Overall, the service users in this house were more able than in the other houses, and this was reflected in their higher mean ABAS-II score. Previous research highlights that the more able service users are, the more support they tend to receive (Jones et al., 1999; Jones et al., 2001; Smith et al., 2002). As a result, AS has often been found to be less effective than it is for more severely disabled service users. This is likely to account for the limited change observed in house (c). Of note is that recently those people living in this service have moved into supported living, with approximately two hours of staff support per day. Mansell & Beadle-Brown (2012) reviewed 24 AS studies and of these, even after training, only 3 had comparable levels of engagement to this particular service at baseline. Looking at the effect of the intervention across environments, the multiple baseline design helps to highlight the apparent relationship between the timing of the intervention and the increase in engagement levels. With the exception of house (c), all of the other houses showed an increase in engagement levels which coincided with implementation of the training. The engagement levels in houses (a), (b), and (d) were in the range 60-69% following AS training. Studies that have been published in settings with similar levels of adaptive functioning show post intervention engagement levels in the range of 26-77% (Beadle-Brown et al, 2012; Bradshaw et al, 2004; Jones et al, 1999; Jones et al, 2001; Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008; Stancliffe et al, 2007; Totsika, Toogood, Hastings, & McCarthy, 2010).

The levels of staff assistance also increased significantly from baseline to follow-up across the service. Again House (c) showed little change, and it could be hypothesised that with less dependent service users there was less requirement for staff assistance in order for them to take part in activities. Mansell & Beadle-Brown (2012) also reviewed 10 studies of AS where staff assistance following training was reported. The overall percentage of staff assistance at baseline in the current study was higher than in any of these studies, indicating that even prior to training staff assistance was at least comparable to those found in 'trained' services. Putting the data from house (c) to one side, the staff assistance levels for the remaining houses was in the range 16-35% post intervention. In services with similar levels of adaptive functioning it was 9-16% (Beadle-Brown et al, 2012; Bradshaw et al, 2004; Jones et al, 1999; Jones et al, 2001; Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008; Stancliffe et al, 2007; Totsika, Toogood, Hastings, & McCarthy, 2010).

On the IC the results also showed moderate effect sizes for positive and negative interactions between staff and service users, following AS training. Only service (a) showed no effect in terms of positive interactions, albeit that they had increased marginally. The analysis of the individual dimensions of the IC provided a more detailed picture about which aspects of the interactional style were most influenced by the training. In terms of negative interactions, it is clear that passive inattention was the predominant negative characteristic of staff's interactions with service users, and that it decreased following training. The positive interactions showed a more interesting and varied pattern. Interactions that were coded as 'positive' most commonly reflected the characteristics of verbal and non-verbal warmth.

1.4.2 Linking the Findings with Other Studies

It is useful to consider the results of the current study within the context of the existing AS literature. Engagement levels at baseline, and following AS training have been evaluated across many different studies. Mansell and Beadle-Brown (2012) summarised datasets on engagement levels from an available 24 studies, conducted between 1990 and 2011. They concluded that prior to any AS intervention, the average engagement level was 39%. The overall engagement level at baseline in the current study was considerably higher at 55%. There are some reasons why baseline engagement levels may have been higher in the current study, compared with other research. The service has some unique characteristics that might be advantageous in promoting engagement. Levels of challenging behaviour tend to be fairly low in comparison to many UK settings, historically because people with more severe challenging behaviour were often moved to out of area placements in the UK, with limited opportunities for repatriation.

Staffing characteristics is another factor which may have contributed positively to engagement levels. There appears to be a well balanced mix of staff skills within the service, with a combination of well qualified young staff and more experienced staff. This has arisen in part from a recent drive to recruit new staff, many of whom are well qualified young people with social and health care degrees. Recruitment of this staff group has had a specific focus on a positive values base, enthusiasm to work with people with learning disabilities, and motivation to put academic theory into practice. This has complemented the existing staff pool, many of whom have worked for a long time with service users, developing trusting relationships and a good understanding about how best to support individuals. When comparing engagement levels following

AS training, the pattern of change appears to be consistent with other studies (e.g., Jones et al., 1999; Jones et al., 2001; Stancliffe et al., 2007).

In terms of comparing the results from the IC, there is a limited literature to draw from. McLaughlin and Carr (2005) examined the impact of rapport on service users' problem behaviour, and found that when rapport improved, service users' compliance with difficult tasks increased, and their problem behaviour decreased. The results of this study sit nicely alongside these findings. Both show an emerging picture of an association between positive rapport and increased engagement in meaningful and/or potentially demanding tasks. Quite how robust this association is, or what the underlying mechanisms are, is an area that warrants further research.

1.4.3 Study Limitations

The process of conducting the study has revealed a number of limitations of the research design and methodology, which warrant further discussion. First it is important to highlight difficulties that became evident with the multiple baseline design. The challenges involved in collecting observational data in real life settings are considerable, and unfortunately significant gaps in the collection of baseline data meant that there was no overlap between intervention in one service and baseline in others. This limits the extent to which experimental control can be demonstrated.

There are also some unique characteristics of the service setting, which may have had an effect on aspects of the study. The service operates in a restricted, but densely populated area. A consequence of this for the learning disability service is that all areas within the service are highly accessible to each other (i.e., within a 10 minute drive), with a staff group who have frequent crossover with each other, both professionally and personally. The effect of this is that community homes tend to be 'less boundaried' than they might be in other parts of the UK. There is a high crossover

of staff between environments, and with strong professional and personal links between areas, it is difficult to 'confine' training effects to specific homes. This was recognised as a potential disadvantage of the multiple baseline design, which relies on training effects being confined to specific areas. While the design demonstrated a reasonable pattern of co-occurrence between the dependent variables and independent variable (introduction of training across settings), it may be that this effect was weakened by a 'contamination' of training across environments.

Another potential difficulty associated with a small service was the crossover of roles that occurred within the study. There was a small pool of appropriate professionals to conduct the research, and therefore some were required to fulfil more than one role in the project. For example, some professionals were required to act as both coaches and observers, at different times in the study. This raises obvious concerns about the extent to which observers were 'independent and objective', and also how much staff's behaviour was unduly influenced by the presence of an observer who had previously been their coach. This was a clear weakness in the study, and must be recognised as such. It highlights a common difficulty of resource constraints, which often exists in studies that are conducted in natural, real-life settings.

As the study proceeded, another question began to emerge about whether the video informed reflective practice was different enough to standard AS coaching, and whether it focused sufficiently on the process of relationship building. When the study was designed, it was argued that the *process* of video reflection was sufficiently different from standard AS coaching, because it enabled staff to reflect on, and appraise their *own* performance, in a way that was more difficult to achieve in the standard coaching format. In reviewing the study there is still good reason to think that this position was justified. Firstly, other researchers had highlighted that facilitating self-

reflective practice was an important area for future focus in the AS literature (Mansell & Beadle-Brown, 2012). Secondly, anecdotal feedback from the staff in this study suggested that it was indeed a useful method for helping them to achieve this. However, in the future there is room for refinement of the video informed coaching process, to further explore variables specific to rapport building aspects of interactions. Asking more explicit questions about the relationship, and encouraging reflection about the link between service user behaviour and staff member's emotional responses might help staff to 'scaffold' this thinking in a more constructive way. Some examples of 'scaffolding' questions might include for example, "How were you feeling when she (service user) was doing that?..."Were you aware of feeling like that at the time?"..."How do you think that influenced what you did next?"..."How do you think the service user was feeling at that point?"

The use of the IC is another area of the study that warrants critical examination. One of the aims of the current study was to pilot a method for measuring the quality of the relationship between staff and service users. The IC was designed to be a set of codes that could begin to 'shine the spotlight' on the relationship component of AS, and to stand alongside the better established codes for activities (Jones et al., 1999). The checklist was designed to draw on existing methodologies, such as DCM (Kitwood & Bredin, 1992) and the Positive Interactions Checklist (Vanono et al., 2013) as a starting point in this process. Analysis of data generated from the IC suggested that it was a useful preliminary step. Broadly speaking, the checklist helped to demonstrate that AS can positively influence some aspects of the ways in which staff relate to the people that they support. However, more detailed analysis of the different dimensions of the checklist suggested that some of the codes 'captured the picture' of staff interactions in a more helpful way than others. The negative interaction that was 'captured' by the

checklist was predominantly passive inattention, with low levels of the other dimensions observed. This suggests that some of the codes may warrant elimination, or further refinement.

There is also a broader question at play about the extent to which the complexities of relationships between people can be reduced down to a set of behavioural codes. It could be argued that this is too much of a reductionist approach to understanding human relationships. However, it is difficult to conceptualise how else this question could be approached, in a way that retains an objective and systematic approach. McLaughlin and Carr (2005) used a variety of different methods to establish 'good' and 'poor' rapport dyads. One method involved the service user making a 'preference rating' of staff members, using a choice paradigm. They also asked staff members to rate their colleagues level of rapport, as an alternative measure of relationship quality. Finally, they asked staff themselves to provide ratings of their own perceived relationship strength, using a five point likert scale. An additional approach to triangulating the results from the IC could be to use some of these alternative methods. For example, asking staff to rate their own interactions with service users, or asking colleagues to provide ratings of their perceived rapport building skills. This information could be compared with behavioural observations generated from the IC, to help provide information about the validity of the measure.

An alternative approach to measuring the quality of interaction between staff and people with profound learning disabilities has been explored by Hostyn, Petry, Lambrechts and Maes (2011). They piloted the use of an attachment framework, taken from research on parent-infant relationships. They videotaped staff-client interactions, and coded the quality of relationship using two measures. The Emotional Availability Scales (Biringen et al., 1998, cited in Hostyn et al., 2011) were used to evaluate the staff

member's quality of attunement in interactions, using six dimensions (sensitivity, structuring, non-intrusiveness, non-hostility, and responsivity and involvement of the client). The Maternal Behaviour Rating Scales (Mahoney et al., 1992, cited in Hostyn et al., 2011) measured four factors related to interactive style. Broadly, these related to the following areas: sensitivity to the person's interest, warmth of affect and expressiveness, use of praise, and appropriate use of pace. While this appears to be a potentially useful framework to apply, there are questions about its practical applicability on a day to day basis. One of the potential advantages of using a set of behavioural codes, such as those contained in the IC, is the ease in which they 'slot' into the existing framework of behavioural codes that are already well established and widely used in the evaluation of AS, and the extent to which they can be used in direct observational methodologies.

1.4.4 Local Service context

At this point it would be helpful to put these results into the local service context. This project was developed by the PBS team, early in its formation. The team was developed to support service users who display challenging behaviour, using a PBS philosophy and approach to intervention. AS is viewed as a primary preventative strategy within the PBS model, and considered to be an important component for *preventing* challenging behaviour (Jones et al., 2013). By engaging in meaningful activity more often, service users tend to receive more positive staff attention, develop and learn new skills, and have an opportunity to exert more choice and control within their environment, all factors that can act as 'setting events' for challenging behaviour when they are absent. When the PBS team first sat down to create service delivery priorities, they were clear that they wanted to have a broad systemic focus, with an emphasis on staff training, and on promoting practices designed to *prevent* challenging

behaviour. Until this point there had been little offered in the way of formal staff training in PBS approaches, and there was evidence from staff themselves that they would value such training. It was also clear that services would benefit from a more organised and planned approach to the way that they delivered care.

The current project developed out of this context, and it is encouraging to see that the systematic delivery of a staff training programme has led to improvements in the quality of life of service users. There is evidence that service users are engaging more often in meaningful activities, and there is also evidence that they are experiencing a more positive interactional style with staff. Given that many of the service users in residential care have limited peer or family relationships, this positive social contact with staff is a vital component for enriching their lives. Staff themselves have been positive about the impact of the training. While it has been beyond the scope of the current project to formally collate their views about the training, some comments have been recorded below, that 'capture the essence' of the video coaching component:

"The video coaching helps us to see things from a different perspective".

"I found video feedback better than verbal feedback...we can see for ourselves what we need to improve on..and what we do well".

 "Watching the video, I could see that I was talking too much..and that didn't help X know what to do"

"I could see why X got frustrated..it helped me to understand how he was feeling"

A family member observed that "the staff keep a record now of all the time that they spend with him (son)...now his day is filled with activities rather than being left to his own devices...he's a lot happier in himself".

One of the biggest challenges in implementing AS in services is the maintenance of positive changes across the long-term. Previous research highlights the importance of

managers and senior staff having a strong 'practice leadership role' and presence on the shop floor, to continue to model and coach staff (Mansell et al., 2005). With this in mind, the PBS team has launched an 'AS network' within the service, which will be responsible for continuing to develop and maintain AS across the organization. House managers, together with staff from different settings come together regularly to review videos and reflect on their practice. There are also plans to extend AS training to other parts of the service, such as supported living, and day service teams. By creating such procedures, it is hoped that AS will become more 'embedded' within the culture of the organization, rather than viewed as a time-limited project.

1.4.5 Future Directions

The development of positive relationships between staff and service users is clearly an important area, and one that is best not left to chance. Despite this, there has been little research that looks systematically at how staff can build positive and enabling relationships, or objective methods for evaluating this aspect of staff's support. The current study is a preliminary step in this direction. However, further research is warranted, and there is an expectation that the research community can build on the initial steps that have been undertaken in this study.

In the future it would be helpful to explore in more detail how changes in positive interactions might be related to the variable of engagement. It would also be interesting to trial the IC with a population that presents higher levels of challenging behaviour, to establish whether some negative interactions, rarely observed in this study, are more present in other populations. Alternatively the IC might benefit from further refinement, to modify or remove categories that are rarely coded. The reflective video coaching procedure makes a useful addition to the tool kit that staff teams can use to promote the development of enabling relationships, and again would benefit from

further evaluation and refinement, to maximise the opportunity for staff to reflect on the key components of positive relationships.

1.4.6 Summary and Conclusions

In summary, this study has made a number of valuable contributions, both to the local provision of learning disability services, and also to the wider literature on AS. Locally, the project has helped to establish AS within residential services, and demonstrated that this has had a significant impact on service user involvement in meaningful activities, and the style of support that staff provide. It has also introduced a framework for helping staff to reflect on their practice, and to pay attention to the process of building positive relationships with the people that they support. These service improvements have occurred without any additional staff resources, a factor that is important to highlight in a difficult financial climate.

On a wider level, the project has made a contribution to the AS literature, highlighting the benefits of focusing on the relationships that staff build with service users, in addition to the more standard components of AS. The video informed reflective coaching makes a useful practical addition to the resources that staff can use when implementing AS, and the IC is a tool that holds promise for helping services to better evaluate the process of relationship building between staff and the people that they support.

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Appendix A

Ethics approval form

HEALTH AND SOCIAL SERVICES
A STATES OF GUERNSEY GOVERNMENT DEPARTMENT

IJG/C5.4

Health and Social Services
Corporate Headquarters
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St Andrew's, Guernsey
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Pip Appleton
Clinical Psychologist
Community Adult Learning Disability Team
Professor Shaw Community Centre
La Rue Maze
St Martin's
GY4 6RR

6 December, 2013

Dear Pip

Facilitating Relationship Building in Active Support: An Evaluation of Enhanced Active Support Training in Residential Learning Disability Services

Firstly, I would like to apologise for the delay in formally writing to you regarding the above research study.

Thank you for attending the Ethics Committee meeting on Thursday 11 July, 2013 to discuss your study application study. At the meeting, the following documents were reviewed by the Ethics Committee:

a) Letter from Pip Appleton, Clinical Psychologist, Community Adult Learning Disability Team (dated 28 June, 2013);

b) Project Proposal (dated 1 July, 2013);

c) Participant Consent Form;

d) Family Notification Letter;

e) Information Sheet for Staff;

f) Adaptive Behavior Assessment System Second Edition (ABAS II);

g) PBS Clinical Practice and Outcomes [P-CPO 2008];

h) CV Philippa Appleton.

Members of the Committee were please to have had an opportunity to meet you, to hear your summary of the proposed study and to ask questions.

POLITICAL RESPONSIBILITIES

Promoting, protecting and improving health for all, through the provision of Hospital, Community, Social and Public Health Services

On behalf of the Ethics Committee, I am pleased to confirm that the Committee agreed to approve the study.

In order to track progress of approved studies, the Ethics Committee would be grateful if you could provide regular progress reports for the study (at least annually) and / or a final report following its completion. This should be forwarded to: Ian Gaudion, Executive Assistant (Committees), Health and Social Services Department, Corporate Headquarters, Rue Mignot, St Andrew's, GY6 8TW.

The Committee and I wish you every success with your trial.

Yours sincerely

Mrs Tracey McClean
Chairman, Ethics Committee

2

Appendix B

Accessible information sheet for consent

Resident Consent Form

We want to find out how many activities you do at the moment.

We would like to help staff help you be involved in activities.
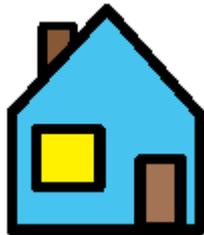
Somebody will come to your house and watch you and your staff.

You can tell us to stop any time.

Staff will fill out some forms about what you can already do.

Staff will practise working with you in a different way and this might be videotaped.

We will tell other people about how well the staff in your house help you.

We will not tell other people anything private about you.

We can talk to you about the project after it is finished.

You do not have to be involved if you do not want to. It is your decision.
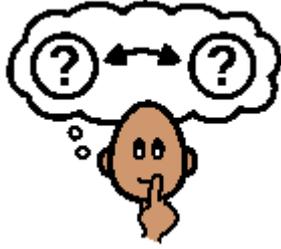
I agree to take part   I do not agree to take part

Appendix C

Letter of information to families

Address
Date

Re: Resident Name

Dear Name,

We are planning to train staff in helping people who live in residential services.

We would like to find out how many activities service users do at present.

The training will teach staff how to be better at:

- Managing their time to maximise time spent with residents.
- Plan activities
- Help people do activities for leisure and day to day living.
- Empower service users with more choice.

Staff will fill out questionnaires about what residents are able to do currently.

The work will involve external HSSD staff going into residential homes to observe staff and residents in the home.

If anyone shows any sign of distress at the observer's presence, the observation will be stopped.

Results will be presented per house, not per individual resident.

All individual information will remain confidential.

Results will be available upon request after the project finishes.

Please phone Pip Appleton on 01481 230 000 if you have any further questions or concerns.

Yours Sincerely,

Pip Appleton	Will Jones
(Clinical Psychologist)	(Team leader & Lead PBS Support)

Appendix D

Video Reflection Checklist

Preparation:	
• Was the activity meaningful to the service user?	
• Was the timing of the activity appropriate?	
• Was the activity planned out beforehand?	
• Were distractions kept to a minimum?	
• Did the activity take place in an appropriate environment?	
What went well?	**What could be improved?**

Presentation:	
• Were most opportunities to involve the service user taken?	
• Was the environment used to help the service user understand what to do?	
• Was non-verbal communication used clearly?	
• Did verbal communication match the service user's level of understanding?	
• Did the staff notice attempts made by the service user to communicate and respond appropriately?	
What went well?	**What could be improved?**

Assistance:	
• Was the service user given enough time to respond before staff intervened?	
• Did the staff provide enough assistance to help the service user succeed?	
• Did staff move on quickly and give more support when required (rather than repeat failed instruction)?	
• Did staff provide support in a way that the service user felt comfortable with?	
• Did the service user experience success in completion of the tASk and was s/he made to feel valued?	
What went well?	**What could be improved?**

Style of support:
- Did staff give the service user their full attention?
- Did staff appear to enjoy the interaction?
- WAS the interaction warm, friendly and respectful? (avoid nagging or being bossy)
- WAS humour and praise used appropriately?
- Did the staff respect decisions made by the service user during the process?
- WAS challenging behaviour managed in a calm manner?

What went well?	What could be improved?

Set Goals:	Review Goals:
Signed by Coach:	Signed by Staff Member:
Date:	Date:

Appendix E

Behavioural codes for staff and service users

1) Staff behaviour:

a) *Assistance* comprised explicit instruction to perform activity (e.g. 'pick up the spoon'), implicit instruction (e.g. questions about what step of the activity comes next) or presentation of materials in the context of an activity (e.g. handing a service user a towel to dry their hands), gestural prompting of an activity (e.g. pointing to the tin to be put in the cupboard), demonstration (e.g. showing the person what to do and then prompting him or her to do it), physical prompting or guidance (e.g. giving hand over guidance as a resident pours a cup of tea), guiding or arranging the materials being used by the resident in an activity (e.g. holding an item steady on a chopping board as a resident cuts it), or giving corrective feedback containing guidance or instruction.

b) *Praise* comprised verbal, gestural or physical praise (e.g. saying 'Good!', signing 'That's right' or patting the service user on the back).

c) *Restraint* comprised physical or verbal disapproval without correction or physically preventing activity (e.g. saying 'No', holding a service user's hands down or saying the service user's name in a controlling manner).

d) *Other conversation* comprised all other interactions neither encouraging nor discouraging of activity (e.g. pleasantries).

e) *Processing* comprised doing something to a service user without assisting their participation (e.g. dressing a service user or holding a service user by the hand while walking).

f) *Disengagement* comprised any other activity that did not involve attention directed at the service user

2) Service user behaviour:

a) *Social engagement* comprised recognizable speech or attempts to speak, signs, gestures or other attempts to gain or retain the attention of another person (except by challenging behaviour), or the giving of attention, AS evidenced by eye contact or orientation of the head, to another person who is reciprocally interacting.

b) *Non-social engagement –domestic* comprised getting ready for, doing or clearing away a household or gardening activity (e.g. washing clothes or setting the table).

c) *Non-social engagement –personal* comprised getting ready for, doing or clearing away a self-help or personal activity (e.g. brushing teeth).

d) *Non-social engagement – other* comprised doing or clearing away a recreational activity, the content of which could be coded under the two codes above (e.g. matching colours).

e) *Challenging behaviour* comprised self-injury, aggression to others, damage to property, stereotypy or other inappropriate behaviours (e.g. public mASturbation, stripping, spitting, pica, tugging at someone or pestering/pushing/ pulling a person).

f) *Disengagement* comprised all other behaviour (i.e. when not engaged socially, non-socially or in challenging behaviour), including no activity, passively holding materials, walking/ wandering outside of the context of an engagement activity, smoking and unpurposeful activity (e.g. manipulating materials to no apparent purpose, minor self-stimulation, talking quietly to self, fiddling with buttons or picking at clothing).

Interaction Checklist

Positive Interaction categories:

1. **Attention:** staff member attends to the service user, and actively engages in an interaction with them; demonstrates that they are 'present in the moment' with the outcome that the service user feels heard, valued, and respected during these interactions. E.g., staff member appears to be listening when service user speaks (demonstrated by appropriate response back), greets service user when first meets, directs eye contact and body language towards service user, interprets or responds to actions of service user AS an intentional communication strategy.

2. **Verbal Warmth:** staff member uses words to express to the service user that they are considered positively e.g., the use of praise, terms of endearment that are likely to contribute to the service user's positive self- image and sense of acceptance.

3. **Humour:** staff member uses humour during interactions with the service user. Humour is used with the intention of making the service user laugh, feel at ease, or de-escalate a situation. e.g., telling a funny story or joke, referring to a previous incident that was amusing for the service user, doing humorous actions.

4. **Non-Verbal Warmth:** staff member uses non-verbal actions, expressions or gestures that convey warmth and acceptance to the service user e.g., animated facial expressions, smiling, positive touch such AS pats, hugs, high-fives, thumbs-up, clapping. Positive movement designed to motivate and engage service users in an activity e.g., dancing or swaying in time to music.

5. **Choice:** staff member offers service user a personal choice, or an alternative course of action from what they are currently doing e.g., would you like apple or orange juice? Do you want to keep doing the puzzle or shall we do something else?

6. **Facilitation:** staff member offers service user help, dictated by their individual level of need. This assistance is given willingly and timely according to need at that moment. Include staff actions (e.g., modelling, prompting) or staff comments that are intended to help the service user to have a better understanding of a situation, or become more competent in a particular skill.

7. **Positive Behavior Support Interactions:** when staff are faced with behaviour that challenges services, they manage the episode with dignity and respect. Staff employ only positive and non-aversive approaches to behaviour management. E.g., use of re-direction, interrupting an escalating chain of behaviours, continuing with positive conversation and actions in the face of comments/actions intended to gain a negative response, remaining calm, maintaining average voice tone and volume, actively following existing PBS protocols/careplans.

Negative Interaction categories:

1. **Inattention:** the staff member does not make any active attempt to interact with the service user. Staff member ignores the service user, and continues with an activity or conversation as if the service user weren't there, or actively withholds attention or assistance when the service user expresses a clear need for contact e.g., by looking or walking away.

2. **Verbal Hostility**: staff member uses words with the intention of intimidating and frightening the service user, or uses words that are likely to contribute to a service user feeling incompetent, useless, worthless, or incapable. E.g., telling the service user that they are going to be in trouble with authority figures, telling the service user how much better someone else can do a particular activity.

3. **Mockery**: staff member uses humour with the intention of teasing, humiliating, and making fun of a service user.

4. **Non-Verbal Hostility:** staff member uses non-verbal actions, expressions, or gestures that convey dislike and rejection to the service user. E.g., facial expressions such as scowling or frowning, actively resisting touching the service user when there is a clear need to, making rude gestures such as "giving the fingers", turning away from the service user in a way that conveys dislike.

5. **Lack of Choice:** staff member denies the service user an opportunity to make an informed choice for themselves. E.g., staff member forces a service user to do something, over-rides service user's clear desires or wishes, provides information about choice in a way that prevents the service user from understanding sufficiently (ie information provided is too complicated, presented too fast, or is not presented in a format that the service user can understand), or uses deception to manipulate the service user into making a certain choice.

6. **Direction:** staff member carries out care for the person without actively involving them in the process. No attempts are made to teach the engage or teach the individual

7. **Restrictive Practice Interactions**: when staff member is faced with behaviour that challenges services, they respond in a restricting or punishing manner. e.g., the use of physical, mechanical, or chemical restraint, removing (or threatening to remove) something positive, such AS placement in seclusion or taking away favourite food/activity items, applying positive punishment, such AS doing something to the service user that is aversive or inflicts pain or physical/emotional harm. Actively avoids following existing PBS protocols/careplans.

2.0 Systematic Literature Review

The psychological outcomes of mindfulness based therapies for people with Autistic Spectrum Disorder

Word Count: 5,503

Abstract

Co-morbid psychological difficulties, such as depression, anxiety, and challenging behaviour are common in people with Autistic Spectrum Disorder (ASD). There is a need to identify effective psychological interventions for this population, and mindfulness based therapies (MBT) have been trialled in a number of studies. The aim of this review was to describe and synthesise the literature examining the outcome of MBT on the psychological functioning of people with ASD. A systematic literature review was conducted, using the Preferred Reporting Items for Systematic Review and Meta Analysis (PRISMA) guidelines. Five electronic databases were searched, including Medline, Scopus, Psyc Extra, Web of Sciences, and Psyc Info. Application of the inclusion criteria identified eight empirical studies (n = 162 participants). All studies were conducted within the last eight years. The results showed reductions on measures of anxiety, depression, rumination, and problem behaviour, and increases on measures of quality of life and positive affect. Overall quality of the included studies was mostly weak, with a lack of randomised controlled trial (RCT) studies (n = 1), reliance on quasi-experimental designs, and small sample sizes. These methodological difficulties limit the conclusions that can be drawn. Future research needs to include larger more rigorous clinical trials, and the use of qualitative methodologies.

2.1 Introduction

2.1.1 Autistic Spectrum Disorder (ASD)

The recently revised DSM-V diagnostic criteria describe ASD as a dyad, consisting of difficulties in social communication and social interaction, together with restricted and repetitive behaviour interests, or activities (American Psychiatric Association, 2013). ASD is categorised as a pervasive developmental disorder, and while it is usually first diagnosed in childhood, increasing attention is being directed to its prevalence and clinical presentation among adults (Hofvander et al., 2009). People with ASD present with a wide and varied range of difficulties, which commonly include atypical language development, difficulties with socio-emotional functioning, and cognitive deficits in areas such as social perception, executive functioning, and information processing (Lai, Lombardo & Baron-Cohen, 2014). The prevalence of ASD has been steadily increasing over the past two decades, with the most recent estimates close to 2% (Kim et al., 2011).

2.1.2 Co-occurring conditions

More than 70% of people with ASD have co-occurring medical, developmental, or psychiatric conditions, and generally the more co-occurring conditions the greater the person's disability (Lai et al., 2014). Co-morbid psychiatric disorders commonly include other neurodevelopmental disorders such as attention-deficit hyperactivity disorder (ADHD) and Tourette's Syndrome (Pahnke, Lundgren, Hursti & Hirvikoski, 2014). Behavioural disorders, such as oppositional defiant disorder (ODD) have been shown to be common in children and adolescents with ASD, with prevalence rates of between 28-44% (Mattila et al., 2010; Simonoff et al., 2008). Many children with ASD show challenging behaviour, again with rates as high as 45% (Poppes, Putten & Vlaskamp, 2010). For some, these behaviours will persist into adult life with

challenging behaviours, especially aggression, often creating major barriers to independence and quality of life (Singh et al., 2011a).

Co-morbid anxiety disorders are also common in childhood (Mattila et al., 2010; Simonoff et al., 2008), with associated high risks of insomnia in adolescents compared to normally developing teenagers (Mattila et al., 2010). There is evidence that anxiety problems often persist into adulthood, with reported rates of 42%-56% (Lai et al., 2014). Kanner (1943) suggested that features of ASD, such as a desire to engage in routine and repetitive behaviours, might be linked to anxiety in some way. Other explanations have also been offered, including the hypothesis that people with ASD experience high rates of anxiety because they do not have the coping skills required to manage stress (Groden, Levasseur & Baron, 2002). Mood disorders such as depression are also common in adults with ASD, with studies reporting that approximately half of adults in clinical settings have a co-occurring mood disorder (Hofvander et al., 2009; Joshi et al., 2013). Lugnegård Hallerbäck and Gillberg (2011) found that 70% of young adults with Asperger Syndrome have experienced at least one major episode of depression, and 50% have suffered from recurrent episodes.

2.1.3 Psychological interventions

In addition to the emotional costs associated with ASD, there are significant societal and financial costs. In the United States it is estimated that costs related to ASD are close to 90 billion dollars a year (Ganz, 2007) while in the Netherlands financial costs associated with ASD were found to be 27 times higher than typically developing children (Van Steensel, Dirksen & Bögels, 2013). The impact on family functioning is also significant, with parents of children with ASD showing elevated stress levels, approximately four times greater than those of typically developing children (Silva & Schalock, 2012). Given that co-morbid emotional and behavioural disorders are so

common for people with ASD, there is a need for effective psychosocial interventions that are tailored to suit this population (Bishop-Fitzpatrick, Minshew & Eack, 2013). In children with ASD, parent training based on the principles of applied behavioural analysis (ABA) has been the most common approach to manage associated problem behaviours (Matson, Mahan & Matson, 2009). However, as people with ASD progress into adulthood, many of their difficulties from childhood persist and intensify, resulting in poor outcomes across a range of domains, including employment, social functioning, independent living and mental health (Bishop-Fitzpatrick et al., 2013).

Psychosocial interventions in adolescence and adulthood remain limited. Social skills training for young people up to the age of 21 has been shown to improve aspects of social functioning, including overall social competence and friendship quality, but with no effect on co-morbid depression (Reichow, Steiner & Volkmar, 2012). Cognitive-behavioural therapy (CBT) has been adapted for use with people with ASD, in order to address co-morbid difficulties such as depression and anxiety. While the evidence for the efficacy of this approach is small, there are a handful of studies that investigate its effect. Wood et al. (2009) conducted an RCT of CBT for children with ASD and anxiety disorders, which showed positive treatment gains that were maintained at a three month follow up. Other studies have reported that CBT is an effective treatment for adolescents with ASD and co-morbid anxiety (Reaven, Blakeley-Smith, Leuthe, Moody & Hepburn, 2012) and OCD (Russell et al., 2013). Two case studies report positive effects of CBT on symptoms of depression and anxiety in adults (Cardaciotto & Herbert, 2004; Weiss & Lunsky, 2010). Some potential limitations of CBT for this population have been raised. Kiep Spek and Hoeben (2015) highlighted that in some studies participants took a long time to understand the concepts of CBT and to generalise the techniques to real-life situations.

2.1.4 Mindfulness Based Therapies (MBT)

MBTs offer an alternative way to approach psychological difficulties. While MBT and CBT both aim to reduce emotional and behavioural symptoms, their underlying mechanisms differ. MBT form what is now known as the 'third wave of behavioural therapies', which is characterised by an emphasis on awareness and acceptance of present moment experiences. Mindfulness has been defined as "paying attention to experiences in the present moment in a non-judgmental and accepting way" (Kabat-Zinn, 1990). Unlike CBT, MBT places little emphasis on changing the *content* of thoughts, and instead emphasises changing *awareness* of and *relationship* to thoughts (Segal, Williams & Teasdale, 2002). The main mindfulness based approaches are summarised below:

Acceptance and Commitment Therapy (ACT): ACT is a contextual behaviour therapy that is based on relational frame theory, and experimental analysis of human language and cognition (Hayes, 2004). The ACT model proposes that psychopathology is the result of two main processes: responding to thoughts as literal truths (cognitive fusion), and attempting to avoid or control unwanted experiences (experiential avoidance) (Vøllestad, Nielsen & Nielsen, 2012). ACT focuses on increasing psychological flexibility, which includes the ability to experience thoughts, emotions and body sensations non-judgmentally, and to take action towards personally chosen values and goals (Pahnke et al., 2014).

Mindfulness Based Stress Reduction (MBSR): MBSR was developed by Jon Kabat-Zinn (1990). It is an 8 week group based programme where participants practice a variety of mindfulness exercises that are derived from Buddhist mediation practices, but presented in a secular framework (Vøllestad et al., 2012).

Mindfulness-Based Cognitive Therapy (MBCT): Segal, Williams & Teasdale (2002) adapted MBSR and developed an intervention designed to reduce the risk of relapse in people who have experienced at least three previous episodes of depression. This intervention became MBCT, and in addition to a set of mindfulness exercises that are similar to MBSR, MBST incorporates exercises aimed specifically at cognitive processes related to depression.

Dialectical Behaviour Therapy (DBT): DBT was originally developed by Marsha Linehan (1993) for treating people with borderline personality disorder, and has since been adapted for a range of other clinical disorders. The DBT model proposes that difficulties with emotional regulation are central to psychopathology, and the programme includes a range of mindfulness and CBT skills that are designed to improve emotional regulation, distress tolerance, and interpersonal effectiveness (Linehan, 1993).

There are a number of systematic reviews and meta-analyses, including those of randomised controlled trials (RCT), which demonstrate that MBTs are associated with robust improvements in mental health, depression and anxiety in the general population (Fjorback, Arendt, Ørnbøl, Fink & Walach, 2011; Galante, Iribarren & Pearce, 2012; Hofmann, Sawyer, Witt, & Oh, 2010; Vøllestad, et al., 2012).

2.1.5 Applying MBT to people with ASD

The core deficits of ASD are generally thought to originate from impairments in cognitive functioning, however there is considerable controversy about which cognitive processes are affected, and exactly how they map onto the deficits that are observed. There is no one cognitive deficit that can account for the full triad of social, communicative and rigid/repetitive difficulties (Happé, Ronald & Plomin, 2006). Current cognitive accounts of ASD can be divided into two camps, those that propose a

social cognition deficit in theory of mind and emotional processing, and those proposing

a deficit in non-social information processing (Happé et al., 2006). Both of these

theories provide useful insights into the way that people with ASD process information.

Theory of mind (TOM) refers to the ability to attribute mental states to oneself

and to others. The ability to know about minds underlies all social interaction, and is

essential for understanding and predicting the behaviour of others (Yirmiya, Erel,

Shaked & Solomonica-Levi, 1998). Numerous studies have confirmed that most people

with ASD either never acquire, or are late in acquiring the ability to pass TOM tasks

(see Yirmiya et al., 1998 for a review), and this goes a long way to explaining the social

and communicative impairments in ASD.

Executive functioning deficits have also been associated with ASD. Executive

functioning is an umbrella term for a set of cognitive skills that include planning,

working memory, impulse control, inhibition, maintaining and shifting attention, and

self-monitoring action (Hill, 2004). In autism research there is an emerging picture in

which disengagement of attention, mental flexibility, planning and the use of

organisational strategies all appear to be impaired (Boucher, 2009). Abnormal

attentional processes have also been implicated in the literature on weak central

coherence, a theory that postulates that people with ASD show an enhanced ability to

process 'local features' (Happé & Frith, 2006), and an associated difficulty in

broadening the spread of attention (Mann & Walker, 2003).

Studies that have applied MBT to people with ASD argue that mindfulness

training might influence cognitive processes associated with these social and

informational processing difficulties. The pre-frontal cortex has been implicated as an

important structure for regulating these processes (Siegel, 2010). The neuroscience of

mindfulness, while still in its infancy, has consistently shown that the pre-frontal cortex

and brain structures associated with attention and executive functioning show functional and structural changes following mindfulness training (Tang, Hölzel & Posner, 2015). Meditation has also been linked to increased self-awareness and empathy for others (Block-Lerner, Adair, Plumb, Rhatigan, & Orsillo, 2007), a deficit that is associated with TOM. Another central mechanism of change in mindfulness is stress reduction (Kabat-Zinn, 1990). De Bruin, Blom, Smit, van Steensel and Bögels (2015) linked this to the main cognitive processes thought to be impaired in people with ASD: "Under stress our capacity to see the perspective of others (TOM), to keep a sharp focus on the bigger picture (central coherence), and be flexible and organise information (executive functioning) is hampered" (p. 907).

Those advocating an ACT approach also argue that avoidance of aversive thoughts and feelings is a common problem for people with ASD, arising from their vulnerability to stress and experiences of negative life events. This in turn may act to reduce psychological flexibility and narrow behavioural repertoires. An ACT approach may therefore be well suited to this population, assisting people with ASD to improve aspects of psychological flexibility and behavioural rigidity (Pahnke et al., 2014).

2.1.6 The current review

There are currently a number of studies that have examined the outcomes of MBT for people with ASD, however there has been no systematic review of this literature to examine in more detail how effective these interventions have been. This systematic review aims to review the literature on the psychological outcomes of MBT for people with ASD.

2.2 Method

The systematic review of the literature outlining the outcomes of mindfulness-based treatments on the psychological functioning of people with ASD was conducted in

accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Liberati et al., 2009). Prior to the review, the inclusion/exclusion criteria and methods of analysis were outlined within the review protocol.

2.2.1 Eligibility criteria

In order to be included in the review, the following criteria needed to be met:

- The sample included people with ASD
- A mindfulness based therapy was used
- Outcomes relating to behavioural disturbance and/or psychological symptoms for the person with ASD were identified
- It was an empirical study

Non-English papers were excluded from the search. There was no limitation on year of publication. Studies were identified using five electronic databases. The search was applied to Medline, Scopus, Psyc Extra, Web of Sciences and Psyc Info. The literature search was carried out using a combination of the search terms *mindful*, *mindfulness based stress reduction*, *acceptance and commitment therapy*, *mindfulness based cognitive therapy*, *dialectical behaviour therapy*, *meditation*, *autism*, *neurodevelopmental disorder*, *asperger* and *pervasive developmental disorder*.

All articles identified by the search were entered into RefWorks reference management software. Following the removal of duplicate records, titles and abstracts of the identified articles were screened for relevance using the above criteria; with all reasons for exclusion recorded. A second reviewer also undertook the screening to check for reliability, and the two reviewers then met to review results and agree on final full text copies to be obtained. A total of 323 articles were identified and from this 9 were screened as eligible to be included in the systematic review (see Figure 6). One

article was subsequently excluded because it could not be obtained (Sizoo, Glas, &

Kuiper, 2014), leaving eight articles for inclusion.

A data extraction table was developed to extract data from the articles. The data

extracted included characteristics of participants, study design, inclusion criteria, type of

mindfulness intervention, outcome measures used, methods of statistical analysis,

results, and overall conclusions drawn. For reliability purposes these tables were also

checked by the second reviewer.

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┌─────────────────────────────────┐
│ Records identified through       │
│ database searching               │
│ n = 323                          │
└─────────────────────────────────┘
                │
                ▼
┌─────────────────────────────────┐
│ Records after duplicates removed │
│ n = 267                          │
└─────────────────────────────────┘
                │
                ▼
┌─────────────────────────────────┐      ┌──────────────────────────────────┐
│ Records screened                 │────▶ │ Excluded records:                 │
│ n = 267                          │      │  • Not an ASD population (n =     │
└─────────────────────────────────┘      │    89)                            │
                │                         │  • Not a mindfulness based        │
                │                         │    therapy (n = 42)               │
                │                         │  • No therapeutic benefits in     │
                │                         │    terms of behavioural           │
                │                         │    disturbance or psychological   │
                │                         │    symptoms identified (n =       │
                │                         │    18)                            │
                │                         │  • Not an empirical study (n =    │
                │                         │    107)                           │
                │                         └──────────────────────────────────┘
                ▼
┌─────────────────────────────────┐      ┌──────────────────────────────────┐
│ Full text articles eligible for  │────▶ │ Full text articles excluded:      │
│ inclusion                        │      │  • Unreachable records (n = 1)    │
│ n = 9                            │      │                                   │
└─────────────────────────────────┘      └──────────────────────────────────┘
                │
                ▼
┌─────────────────────────────────┐
│ Articles included in systematic  │
│ review                           │
│ n = 8                            │
└─────────────────────────────────┘
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Figure 6. PRISMA flow diagram.

2.2.2 Quality Appraisal

Two independent reviewers appraised the eight selected studies for potential bias. The *quality assessment tool for quantitative studies* (National Collaborating Centre for Methods and Tools, 2008) was adopted (Appendix G). This tool was chosen because it is suitable for use with non-randomised studies, shows acceptable validity and reliability properties (Thomas, Ciliska, Dobbins & Miccucci, 2004), and was recommended as a suitable measure in a systematic review of quality assessment tools by Deeks et al. (2003). The tool provides an overall methodological rating of strong, moderate, or weak, based on ratings across six areas: selection bias, study design, confounders, blinding, data collection methods, and withdrawals and drop-outs (see Table 2).

Table 2

Quality assessment of included studies.

Study	Selection bias	Study design	Confounders	Blinding	Data collection method	Withdrawals and dropouts	Overall rating
Cook (2008)	Moderate	Moderate	N/A	N/A	Strong	Weak	Moderate
De Bruin et al. (2015)	Moderate	Moderate	N/A	N/A	Weak	Strong	Moderate
Hwang et al. (2015)	Weak	Moderate	N/A	N/A	Weak	Weak	Weak
Kiep et al. (2015)	Weak	Moderate	N/A	N/A	Strong	Weak	Weak
Pahnke et al. (2014)	Moderate	Strong	N/A	N/A	Weak	Strong	Weak
Singh et al. (2011a)	Weak	Moderate	N/A	N/A	Weak	Weak	Weak
Singh et al. (2011b)	Weak	Moderate	N/A	N/A	Weak	Weak	Weak
Spek et al. (2013)	Moderate	Strong	Weak	Weak	Strong	Strong	Weak

2.3 Results

2.3.1 Study Characteristics

      Eight studies met the eligibility criteria. One published RCT was identified. There were five published uncontrolled trials using a quasi-experimental design. A multiple baseline across participants design was used for the remaining two studies. No qualitative studies were found. A summary of the characteristics of the studies is provided in Table 3.

Table 3

Summary of study characteristics included in the systematic review.

Study characteristic	No. of studies	
Date of publication		
Before 2010	1	Cook (2008)
After 2010	7	Cook (2008); De Bruin et al (2015); Kiep et al (2015); Singh (2011a); Singh (2011b); Spek et al (2013)
Group study site		
USA	3	Cook (2008); Singh (2011a); Singh (2011b)
Netherlands	3	De Bruin et al (2015); Kiep et al (2015); Spek et al (2013)
Australia	1	Hwang et al (2015)
Sweden	1	Pahnke et al (2014)
Research design		
RCT	1	Spek et al (2013)
Quasi-experimental	5	Cook (2008); De Bruin et al (2015); Hwang et al (2015); Kiep et al (2015); Pahnke et al (2014)
Multiple baseline	2	Singh (2011a); Singh (2011b)
Intervention		
ACT based	2	Cook (2008); Pahnke et al (2014)
MBT-AS	2	Kiep et al (2015); Spek et al (2013)
Mindfulness based	4	De Bruin et al (2015); Hwang et al (2015); Singh (2011a); Singh (2011b)
Parental mindfulness training included		
Yes	4	De Bruin et al (2015); Hwang et al (2015); Singh (2011a); Singh (2011b)
No	4	Cook (2008); Kiep et al (2015); Pahnke et al (2014); Spek et al (2013)

Age of participants		
Child/adolescent (age range 8-15)	1	Hwang et al (2015)
Adolescent/young adult (age range 11-23)	5	Cook (2008); De Bruin et al (2015); Pahnke et al (2014); Singh (2011a); Singh (2011b)
Adult (age range not further specified)	2	Kiep et al (2015); Spek et al (2013)

Abbreviations: ACT, Acceptance and Commitment Therapy; MBT-AS, Mindfulness-based therapy for individuals on the autism spectrum

2.3.2 Methodological Quality

Overall, the quality of most studies was weak, with six rated "weak" and two rated "moderate" (see table 2). Most studies used a quasi-experimental design, with a small sample size. Two studies used a control group (Pahnke et al., 2014; Spek, van Ham & Nyklĺček, 2013), but only Spek et al. (2013) randomly allocated individuals to treatment and control conditions. It was not clear in either of these studies whether the outcome assessors were blinded to the intervention status of participants, or whether participants were aware of the research question. Five of the eight studies did not describe validity characteristics of selected outcome measures, and two did not report reliability properties. Only three studies adequately described withdrawal and drop-out rates, and reasons why this occurred. Treatment fidelity was only monitored in one study (Hwang, Kearney, Klieve, Lang & Roberts, 2015), and it was not clear from any of the included studies whether contamination of intervention was likely. Because of the limited number of high quality intervention studies, all studies were included in the review regardless of their quality (see Table 4).

Table 4

Data Extraction Table for Included Studies

Study	Design	Sample	Diagnosis	Intervention	Control treatment	Outcome measures	Results
Cook (2008)	Quasi-Experimental	n = 7 6 male, 1 female 16-18y (mean age 17)	Asperger Syndrome or Nonverbal Learning Disability (based on previous psychological assessment)	ACT: 8 week group format	No control group	Psychological inflexibility (AFQ-Y) Value Living (VLQ-A) Psychopathology (BSI)	No significant improvement in psychological inflexibility Significant improvement in valued living Significant correlation between decreases in psychological inflexibility and decreases in psychopathology
de Bruin et al. (2015)	Quasi-Experimental	*Adolescents* n = 23 17 male, 6 female 11-23y (mean age 15.8y) *Parents* n = 29 11 male 48-61y (mean age 53.1)	ASD based on DSM-IV criteria and administration of ADOS-G	*MYmind*: 9 weekly 1.5 hour group sessions plus homework. *Mindful parenting training*: based on MBSR practices, 9 weekly 1.5 hour group sessions	No control group	Intervention participation and satisfaction *Adolescents* ASD core symptoms (AQ) Trait mindfulness (MAAS-A) Psychological symptoms (PSWQ, RRS)	*Adolescents* No significant improvements in ASD core symptoms, mindfulness or psychological symptoms Significant decrease in rumination at follow up Significant improvement in quality of life Parent report showed a

18 female 40-59y (mean age = 49.8)		Quality of life (WHO-5) *Parents* ASD symptoms in a social context (SRS) ASD core symptoms (AQ) General mindfulness (FFMQ) Mindfulness in parenting relationship (IM-P) Dysfunctional styles in parenting (PS) Skills to manage children (PSI-C)	significant improvement at follow up for adolescents' social cognition, social communication and preoccupations *Parents* Significant increase post treatment in mindfulness (describing, acting with awareness, non reactivity), mindfulness in parenting relationship (listening with full attention, self regulation in parenting relationship), perception of skills to manage their child (decrease in parental stress) and verbosity At follow up, significant improvements in mindfulness (observing, describing, acting with awareness, non reactivity), mindfulness in parenting relationship

							(listening with full attention, emotional awareness of self and child, self regulation in parenting relationship, non judgmental acceptance of self/child), laxness and verbosity
Hwang et al. (2015)	Quasi-Experimental	n =6 mother child dyads *Children* 5 male, 1 female 8-15y (mean age unknown) *Parents* All female 34-48y (mean age unknown)	ASD, including PDD-NOS and Asperger Syndrome (diagnostic procedure not clarified)	Stage 1: Mindfulness training for mothers; 8 weekly 2.5 hour sessions followed by a 2 month self practice period. Stage 2: Parent mediated mindfulness training for children with ASD; 3 weekly home visits and online meetings	No control group	Level of mindfulness in parents (FMI) Parental perception of parenting stress (PSS) Family quality of life (FQOL) Parental perception of child problem behaviour (CBCL)	Significant increase in parental mindfulness post treatment Significant decrease in parental stress at follow up No significant improvement in family quality of life Significant reduction in child problem behaviour post treatment, and anxiety and thought problems at follow up
Kiep et al.	Quasi-Experimental	n = 50 34 male	ASD, based on ADI-R and	Tailored MBT-AS protocol: 9	No control	Psychological symptoms (SCL-90-	Significant decrease in anxiety, depression,

(2015)		(mean age 42.1y) 16 female (mean age 37.9y)	DSM-IV criteria	weekly 2.5 hour sessions plus 40-60 minutes daily practice 6 days a week	group	R) Rumination (RRQ) Positive affect (positive subscale of the GMS)	agoraphobia, somatization, inadequacy in thinking and acting, distrust and interpersonal sensitivity, hostility, sleeping problems, rumination, positive affect, and an improvement in general psychosomatic wellbeing post treatment, but not at follow up Significant correlation between rumination and change in depressive symptoms pre to post treatment, and between rumination and change in anxiety, depression and general psychological wellbeing between post treatment and follow up
Pahnke et al. (2014)	Quasi-experimental two group trial	n = 28 13-21y (mean age unknown)	Previous high functioning ASD, based on DSM-IV	6 week ACT-based skills training programme: 2	Waiting list group	Behaviours related to stress (The Stress Survey Schedule for Autism and Other	Significant decrease in stress which remained at follow up Significant reduction in

			criteria	40 minute small group sessions per week plus daily 6-12 minutes of mindfulness exercises		Developmental Disorders) Strengths and Difficulties (SDQ) Anxiety, depression and anger (BYI)	hyperactivity, emotional symptoms and anger post treatment Significant increase in prosocial behaviour
Singh et al. (2011a)	Multiple-baseline design	n = 3 14-17y (mean age unknown)	Clinical diagnosis of ASD (diagnostic process not specified)	'Meditation on the Soles of the Feet' Training day for mothers, then individual daily 30 minute training sessions for 5 days conducted by mothers for the adolescents, plus self practice twice a day.	No control group	Instances of physical aggression	Reduction in number of aggressive acts for each dyad (no statistical analysis)
Singh et al. (2011b)	Multiple-baseline design	n = 3 All male 13-18y (mean age unknown)	Clinical diagnosis of Asperger Syndrome (diagnostic process not specified)	'Meditation on the Soles of the Feet' Training day for mothers, then individual daily 15 minute training sessions	No control group	Incidents (occasions that provided the setting for physical aggression) Instances of physical aggression Instances of self	Reduction in number of aggressive acts, and increase in self control for each dyad (no statistical analysis)

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				for 5 days conducted by mothers for the adolescents, plus self practice twice a day.		control	
Spek et al. (2013)	RCT	n = 42 (41 completed study)	ASD, based on ADI-R and DSM-IV criteria	MBT-AS: 9 weekly 2.5 hour sessions plus 40-60 minutes meditation daily 6 days a week	Control group, matched on verbal ability	Psychological distress (SCL-90-R) Rumination tendencies (RRQ) Positive general affect (GMS)	Significant decrease in depression, anxiety and rumination Significant increase in positive affect Significant correlation between changes in rumination and changes in depression and anxiety

Abbreviations: DSM-IV, Diagnostic and Statistical Manual of Mental Disorders 4th Edition; ADOS-G, Autism Diagnostic Observation Schedule-Generic; ASD, Autism Spectrum Disorder ; AQ, Autism Questionnaire; MAAS-A, Mindful Attention and Awareness Scale-Adolescent Version; PSWQ, Penn State Worry Questionnaire; RRS, Ruminative Response Scale; WHO-5, World Health Organisation-Five Wellbeing Index; SRS, Social Responsiveness Scale; FFMQ, Five Facet Mindfulness Questionnaire; IM-P, Interpersonal Mindfulness in Parenting Scale; PS, Parenting Scale; OSI-C, Parenting Stress Index-Competence Scale; PDD-NOS, Pervasive Developmental Disorder-Not Otherwise Specified; FMI, Freiberg Mindfulness Inventory; PSS, Parenting Stress Scale; FQOL, Beach Family Quality of Life; CBCL, Child Behaviour Checklist; MBT-AS, Mindfulness-based therapy for individuals on the autism spectrum; SCL-90-R, Symptom Checklist-90-Revised; RRQ, Rumination-Reflection Questionnaire; GMS, Dutch Global Mood Scale; ACT, Acceptance and Commitment Therapy; SDQ, Strengths and Difficulties Questionnaire; BYI, Beck Youth Inventories; SUPS, Subjective units of parenting satisfaction; SUIS, Subjective units of interaction satisfaction; SUUM, Subjective units of use of mindfulness; MBPBS, Mindfulness based positive behaviour support; PSS-10, Perceived Stress Scale-10; ADI-R, Autism Diagnostic Interview-Revised; AFQ-Y, Avoidance and Fusion Questionnaire for Youth; VLQ-A, Valued Living Questionnaire for Teens; BSI, Brief Symptom Inventory.

2.3.3 Participant Characteristics

Across the eight studies, there were 162 participants. Five studies included adolescents/young people, ranging in age from 11 to 23. One study included children aged 8 to 15, and the remaining two studies included adults. Not all studies provided information about gender, but from those that did ($n = 92$), 68 were male and 24 were female. It was difficult to calculate data about diagnostic groups, because different studies used different diagnostic criteria. However, studies included participants with a diagnosis of either ASD, Asperger Syndrome, or Pervasive Developmental Disorder-NOS, with the exception of Cook (2008) who also included participants with a diagnosis of Non-Verbal Learning Disability.

2.3.4 Outcomes on Psychological Functioning

Five studies (Cook, 2008; De Bruin et al., 2015; Kiep et al., 2015; Pahnke, et al., 2014; Spek et al., 2013) were found that focused on outcomes associated with psychological functioning and co-morbid symptoms. Spek et al. (2013) was the only RCT study. They adopted an existing mindfulness treatment (MBCT) for adults with ASD, to accommodate differences in aspects of cognitive and emotional functioning, and called it MBT-AS. The treatment protocol closely followed that of MBCT, but omitted cognitive exercises linked to depression, extended the program by a week to account for information processing difficulties, and provided additional support to organise homework tasks. Participants were randomly allocated to an intervention or control group, and controls were offered the intervention at a later date. Participants were only matched on verbal ability, obtained from the WAIS-III, a standardised test of intellectual functioning (Wechsler, 1997), however subsequent analyses revealed no significant differences between age, gender or diagnosis of the groups. Therapists were blind to the randomisation process, and

were reported to have received adequate training to deliver the programme. However, no procedure for assessing treatment fidelity was reported. Drop-out rates were low, with only one participant withdrawing from the intervention group due to illness.

The diagnosis of ASD was made by a trained psychologist who used appropriate assessment tools; the ADI-R to obtain developmental history, and a semi-structured interview with participants based on DSM-IV-TR criteria (APA, 2000). Although the study was reported to include adults, no information was provided about age, either mean or range. Measures relating to psychological functioning were administered before and after the intervention, but there was no follow-up period. Results showed significant reductions on measures of anxiety, depression and rumination in the intervention group that was not present in the control group, and an increase in positive affect compared to the control group. The magnitude of effect sizes was medium to large. There was also some evidence that rumination may have mediated the effects of anxiety symptoms.

The remaining four studies used a quasi-experimental design. Kiep et al. (2015) expanded on the earlier study by Spek et al. (2013), using the treatment data from their intervention group ($n = 20$), and offering the same adapted treatment programme (MBT-AS) to a further 30 participants. No control group was included, however they did include a nine week follow-up period. The same outcome measures were used, and showed a significant reduction in symptoms of depression, anxiety and rumination, and a significant increase in positive affect, from baseline to post-treatment. These changes were maintained across the nine week follow-up period. Rumination was found to be a mediating variable on measures of psychological wellbeing, but not on positive affect.

Three further studies focused on the use of MBT for adolescents with ASD. Pahnke et al. (2014) used an ACT intervention with 28 adolescents from a special school setting.

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Participants were randomised to a control and intervention group, but randomisation was done only be school class, rather than by individual. This allowed for little control of confounding variables, with no attempt to match individuals or classrooms in any way. The six week ACT intervention included twice weekly group sessions, and daily mindfulness exercises in the classroom. The intervention was not delivered by a qualified trainer, and adherence to the treatment protocol was not monitored. Attrition rate was low, with 93% of participants completing at least six of the eight sessions. Outcome measures showed a decrease in self and teacher reported stress, hyperactivity and emotional symptoms in the intervention group, and the group-by-time interaction effects were generally large. These effects were maintained in the two month follow up by the intervention group, while in the control group psychological symptoms generally increased during the follow up period.

De Bruin et al. (2015) administered a mindfulness intervention to 23 adolescents and their parents concurrently. The programme was adapted from the *MYmind* protocol for children with attention-deficit hyperactivity disorder (ADHD), and also included elements from Spek et al.'s (2013) MBT-AS programme. The study included a nine week follow-up period, with good attrition rates reported. There was a significant increase on a self-reported quality of life measure, which remained at follow-up, and a significant decrease in rumination. No significant effects were found on measures of worry, or ASD core symptoms. Cook (2008) conducted an ACT group for a small number of adolescents ($n = 7$) with a diagnosis of either Asperger Syndrome or Non-Verbal Learning Disability, which showed a significant increase on a measure of valued living, but no change on a measure of psychological inflexibility.

2.3.5 Outcomes on Behavioural Functioning

A handful of studies using small sample sizes examined the effect of MBT on the behaviour of children/adolescents with ASD. Hwang et al. (2015) trained six mothers to use mindfulness skills themselves, who then taught their own children (aged 8-15) to use the skills. Outcomes on the Child Behaviour Checklist showed a significant reduction in children's total problem scores at the end of the parent training, with further reductions in thought problems and anxiety at the conclusion of the child training.

Singh et al. (2011a and 2011b) used a multiple baseline design to evaluate the impact of an intervention called *Meditation on the soles of the feet* on the behaviour of adolescents with ASD (Singh et al., 2011a) and Asperger's Syndrome (AS) (Singh et al., 2011b). Again mothers were taught to practice the procedure themselves, before teaching it to their children. Follow-up data on physical aggression by parents and siblings was collected for three (Singh et al., 2011a) and four years (Singh et al., 2011b) post intervention. Singh et al. (2011a) reported that rates of aggressive acts per week dropped from baseline (14, 20 and 16 acts respectively) to 4, 3 and 3 within the 3 year period. Likewise, Singh et al. (2011b) described baseline figures of 2.7, 2.5 and 3.2 aggressive acts per week, compared to the entire four year follow-up period in which no aggressive behaviour was recorded. While the multiple baseline design of these studies enables some level of inference about a causal relationship between the mindfulness procedure and the reduction in aggression, there were also some clear limitations. In addition to the small sample size ($n = 3$), little detail was provided about how the ASD/AS diagnosis was made, and no information about level of intellectual functioning in Singh et al. (2011a). The procedure itself was not clearly linked to a recognised mindfulness intervention, and there

were concerns about the reliability of the data collection process implemented by parents and siblings.

2.3.6 Outcomes on Parental Functioning

Four studies delivered additional mindfulness training to parents. In three studies (Hwang et al, 2015; Singh et al, 2011a; Singh et al, 2011b) parents learnt mindfulness skills themselves and then acted as their own child's mindfulness teacher, and in one study (de Bruin et al, 2015) parents attended a mindfulness group programme in parallel with their children. The results of these studies suggested that there were some additional benefits for parents themselves. In de Bruin et al (2015) parents who attended a parallel mindfulness group themselves showed a significant increase on mindfulness measures at post-test and 9 week follow-up. They also showed a reduction on a measure of parenting stress at post-test, however this was no longer significant at follow-up. A borderline effect on a quality of life measure was found at post-test, however this also decreased slightly at follow-up.

Hwang et al (2015) asked mothers to attend an 8 week mindfulness programme, and then teach the skills to their own children. Overall there was a significant reduction on a measure of parenting stress, however no change on a measure of family quality of life. Singh et al (2011a) taught a *Soles of the Feet* meditation to three mothers, who then taught their adolescents to use it. All three mothers reported changes in their own behavior, such as being able to use the technique to calm themselves when they were stressed. However no quantitative measures were used to assess the effects of the intervention on the monthers themselves. Singh et al (2011b) did not provide any information about the effects of their intervention on the three mothers who learned the procedure and taught it to their adolescents.

2.4 Discussion

The aim of this review was to describe and synthesise research examining the outcome of MBT on the psychological functioning of people with ASD. Application of the inclusion criteria to the search results identified eight empirical studies for inclusion in the review, a surprisingly small number given the recent growth in mindfulness based research, and recognition within the autism literature of the need for evidence based treatments for co-morbid psychological difficulties. However, knowing that the search strategy was conducted in a systematic way gives confidence that all relevant research was included, and that conclusions drawn from this review are based on the synthesis of all available evidence.

Overall, most studies in the review showed that MBT had a beneficial effect on defined psychological outcomes, which included significant reductions on measures of depression, anxiety, rumination, stress, and problem behaviour, and increases on measures of quality of life and positive affect. These improvements were maintained at 8-9 week follow up periods (De Bruin et al., 2015; Kiep et al., 2015; Pahnke et al., 2014), and improvements in problem behaviour were maintained over a three and four year follow-up period in a further two studies (Singh et al., 2011a,b). No change was found on measures of ASD core symptoms, worry (De Bruin et al., 2015), or psychological inflexibility (Cook, 2008).

Looking in more detail at the quality of the studies included, it is clear that there were significant methodological weaknesses that limit the conclusions that can be drawn. The quality assessment tool rated six of the eight studies as 'weak' in terms of overall quality. The studies included in the review generally had small sample sizes, and were likely to be underpowered. Only one study used an RCT design (Spek et al., 2013), and

while it reported medium to large effect sizes for reductions in anxiety, depression and rumination there were a number of methodological flaws. Participants were not matched on demographic variables at baseline, there was no reported monitoring of treatment fidelity, and no detail was provided about the age of participants. Four studies used a quasi-experimental design without a control group, which inherently have a heightened risk of bias and make it difficult to draw conclusions about causality.

The heterogeneity of the included studies also makes it difficult to make comparisons, or to draw meaningful conclusions across studies. Difficulty with diagnostic issues is a common problem in ASD research, because of the frequently changing diagnostic criteria, and controversy over which assessment tools 'match best' with evolving diagnostic criteria. There was considerable variability in the way that ASD was diagnosed across studies, and the ASD sub-groups that were included. While most studies excluded participants with co-morbid intellectual disabilities, some did not. There was wide variability in participants' ages (children aged eight years, through to adulthood), and poor reporting of mean ages, or even range in some studies. There was also wide variation in the mindfulness approaches used, and the way in which they were delivered. Four studies used parent-mediated mindfulness training, making it difficult to untangle the relative effects of the intervention, and to know which components contributed to improvement. This was accompanied by variability in the qualifications and experience of the trainers who delivered the intervention, and poor monitoring of treatment fidelity, which was a feature across the studies. Included studies also focused on a wide range of outcome variables, making it difficult to synthesise or integrate the data in any meaningful way.

While there were clear difficulties with methodological design and heterogeneity across included studies, overall the results of this systematic review suggest that MBT

shows promise for improving some aspects of psychological functioning for people with ASD. These results are consistent with other studies which show that MBT has positive effects on psychological well-being, anxiety and depression in other patient groups, including those with anxiety disorders (Vøllestad et al., 2011), depressive relapse (Fjorback et al., 2011), people with cancer (Hofmann et al., 2010), and family caregivers (Li, Yuan & Zhang, 2016). The follow-up data that is available also suggests that learned skills might be generalising from the teaching environment to real-life settings, a challenge that is often identified when teaching psychological skills to people with ASD (Boucher, 2009).

The results of this review have implications for the future focus of research in this area. The studies so far, while limited in methodological quality, have an important role to play in terms of clarifying logistical issues and paving the way for larger, more rigorous clinical trials. Future studies would benefit from utilising bigger sample sizes, longer follow-up periods, better use of appropriately trained facilitators, and procedures for monitoring treatment fidelity. In terms of outcome measures, it would be helpful for future studies to be more explicit about the reliability and validity properties of assessment tools used, and to include more specialised measures of depression, anxiety, and stress, in recognition that these are the co-morbid difficulties that people with ASD most commonly experience (Lai et al., 2014). None of the studies in this review used a specific measure of depression or anxiety, relying instead on measures of general psychological symptoms. It would be useful to include measures that are most commonly used in other populations, such as the Depression, Anxiety and Stress Scale (DASS), Hospital Anxiety and Depression Scale (HADs), Beck Depression Inventory (BDI), or Perceived Stress scale (PSS), (Hofmann et al., 2010), in order to make comparisons with other populations.

No qualitative studies were identified in the search, and it would be interesting to follow-up the quantitative studies in this review with further qualitative research. One rationale that has been given for trialling MBT with people with ASD is that they struggle to understand and implement aspects of CBT (Kiep et al., 2015). It would be useful to explore in more detail participants' experiences of both approaches, to gain a better understanding of how people with ASD experience the process of CBT and mindfulness. Ultimately the mechanism by which MBT effects change is still under investigation within the general population. How this might apply specifically to people with ASD is as yet unknown, and while there is speculation about how the neural mechanisms underlying mindfulness might influence cognitive processes associated with ASD, such as attentional and executive functioning difficulties, this is all open to future investigation. Further studies could focus more specifically on whether aspects of attention and executive functioning do change for people with ASD following mindfulness training, and if so, how.

Finally, it is important to highlight the strengths and limitations of this review. This study did not include grey literature, so there might be a publication bias against negative results. The review also excluded studies not published in English, and again this created a potential bias in the studies reviewed. However, the review was conducted using a systematic methodology, as advocated in the PRISMA guidelines (Liberati et al., 2009). Two reviewers independently assessed studies for inclusion, and the review also included the use of a risk bias tool to aid the quality assessment process.

2.5 Conclusion

The aim of this review was to systematically identify, evaluate, and synthesise the findings of studies that explored the effects of MBT on the psychological functioning of people with ASD. A small number of studies was identified (n = 8) that met the inclusion criteria. Overall, the quality of most identified studies was weak, with methodological difficulties that included a lack of RCT studies (n = 1), and reliance on quasi-experimental designs, with most studies using small sample sizes. There was large heterogeneity across multiple areas, including age, diagnosis, intervention approach, and outcome measurement, making it difficult to synthesise the data or draw meaningful conclusions.

The results of the studies were generally consistent with those applying MBT to other populations, including reductions on measures of anxiety, depression, rumination, and problem behaviour, and increases on measures of quality of life and positive affect. Overall, the findings suggest that MBT holds promise for helping people with ASD to address the co-occurring psychological difficulties that occur so commonly, and that can have such debilitating effects. Future research needs to include larger more rigorous clinical trials, the use of qualitative methodologies to explore participants' experiences in more detail, and a focus on how the neural mechanisms that underlie mindfulness might influence cognitive processes associated with ASD.

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**QUALITY ASSESSMENT TOOL FOR
QUANTITATIVE STUDIES**

Effective Public Health Practice Project

COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?
1 Very likely
2 Somewhat likely
3 Not likely
4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?
1 80 - 100% agreement
2 60 – 79% agreement
3 less than 60% agreement
4 Not applicable
5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design
1 Randomized controlled trial
2 Controlled clinical trial
3 Cohort analytic (two group pre + post)
4 Case-control
5 Cohort (one group pre + post (before and after))
6 Interrupted time series
7 Other specify _____
8 Can't tell

Was the study described as randomized? If NO, go to Component C.
No   Yes

If Yes, was the method of randomization described? (See dictionary)
No   Yes

If Yes, was the method appropriate? (See dictionary)
No   Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

1

C)   CONFOUNDERS

(Q1)   Were there important differences between groups prior to the intervention?
    1   Yes
    2   No
    3   Can't tell

The following are examples of confounders:
    1   Race
    2   Sex
    3   Marital status/family
    4   Age
    5   SES (income or class)
    6   Education
    7   Health status
    8   Pre-intervention score on outcome measure

(Q2)   If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?
    1   80 – 100% (most)
    2   60 – 79% (some)
    3   Less than 60% (few or none)
    4   Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

D)   BLINDING

(Q1)   Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?
    1   Yes
    2   No
    3   Can't tell

(Q2)   Were the study participants aware of the research question?
    1   Yes
    2   No
    3   Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

E)   DATA COLLECTION METHODS

(Q1)   Were data collection tools shown to be valid?
    1   Yes
    2   No
    3   Can't tell

(Q2)   Were data collection tools shown to be reliable?
    1   Yes
    2   No
    3   Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

2

F)   **WITHDRAWALS AND DROP-OUTS**

(Q1)   Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?
      1   Yes
      2   No
      3   Can't tell
      4   Not Applicable (i.e. one time surveys or interviews)

(Q2)   Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).
      1   80 -100%
      2   60 - 79%
      3   less than 60%
      4   Can't tell
      5   Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

G)   **INTERVENTION INTEGRITY**

(Q1)   What percentage of participants received the allocated intervention or exposure of interest?
      1   80 -100%
      2   60 - 79%
      3   less than 60%
      4   Can't tell

(Q2)   Was the consistency of the intervention measured?
      1   Yes
      2   No
      3   Can't tell

(Q3)   Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?
      4   Yes
      5   No
      6   Can't tell

H)   **ANALYSES**

(Q1)   Indicate the unit of allocation (circle one)
      community   organization/institution   practice/office   individual

(Q2)   Indicate the unit of analysis (circle one)
      community   organization/institution   practice/office   individual

(Q3)   Are the statistical methods appropriate for the study design?
      1   Yes
      2   No
      3   Can't tell

(Q4)   Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?
      1   Yes
      2   No
      3   Can't tell

3

GLOBAL RATING

COMPONENT RATINGS
Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	SELECTION BIAS	STRONG	MODERATE	WEAK	
		1	2	3	
B	STUDY DESIGN	STRONG	MODERATE	WEAK	
		1	2	3	
C	CONFOUNDERS	STRONG	MODERATE	WEAK	
		1	2	3	
D	BLINDING	STRONG	MODERATE	WEAK	
		1	2	3	
E	DATA COLLECTION METHOD	STRONG	MODERATE	WEAK	
		1	2	3	
F	WITHDRAWALS AND DROPOUTS	STRONG	MODERATE	WEAK	
		1	2	3	Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

1	STRONG	(no WEAK ratings)
2	MODERATE	(one WEAK rating)
3	WEAK	(two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No   Yes

If yes, indicate the reason for the discrepancy

1	Oversight
2	Differences in interpretation of criteria
3	Differences in interpretation of study

Final decision of both reviewers (circle one):

1	STRONG
2	MODERATE
3	WEAK

4

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3.0 Service Evaluation Project

The effect of mindfulness based stress reduction (MBSR) on carers of people with

learning disabilities or physical/mental health problems.

Word Count: 7,197

Executive Summary

Mindfulness based stress reduction (MBSR) is a mindfulness intervention, which teaches participants how to reduce stress and manage difficult emotions in a group setting. It is an evidence-based psychological intervention that has been shown to be effective for people with a range of mental health problems, and for assisting people to cope with a variety of physical health conditions. In recent years, MBSR has been utilised with caregivers, recognising that this group make a significant contribution to the care of health service patients, but that they also experience high levels of stress and associated mental health difficulties as a consequence. Most studies evaluating the impact of MBSR for caregivers have focused on parents caring for a child with a disability. There has been little research that examines its impact on caregivers of adults with disabilities or physical/mental health problems.

The current project aimed to evaluate the impact of MBSR on family caregivers of people with learning disabilities or physical/mental health problems, by delivering a pilot group within the local health and social service. A standard eight week MBSR group was delivered to 13 caregivers, of (predominantly) adult service users, who accessed either learning disability, mental health, or physical health services. The outcome of the programme was evaluated in two ways. Firstly, pre and post self-report questionnaires were completed by participants, focusing on mental well-being, quality of life, and ability to use specific mindfulness skills. Secondly, a focus group was conducted with participants approximately two months after the group was completed. Participant's comments were analysed using a qualitative methodology, and summarised into the main themes.

Results of the quantitative analysis showed that the intervention led to a significant improvement in participant's ability to use core skills of mindfulness. No significant change was found on measures of mental well-being or carer quality of life, however there was a trend in a positive direction. The qualitative evaluation revealed interesting themes about benefits that participants identified in aspects of their lives and relationships. They identified benefits from the group process itself, as well as learning new coping skills, and ways of relating to others. Overall, the results of this pilot project are encouraging for the local service. Following this project, the main service recommendation is to pilot a further six month MBSR programme, that extends access to include caregivers, service users, and staff from across the organisation, and which is subject to further evaluation.

3.1 Introduction

3.1.1 Current Literature

Mindfulness based stress reduction (MBSR) programmes form part of what is known as 'third wave' approaches to psychological intervention. MBSR is a standardised training program designed to teach participants how to reduce stress and manage difficult emotions, using a mindfulness approach. 'Mindfulness' refers to a particular type of attention, which includes focusing on the present moment, with non-judgemental awareness, and acceptance of the experience with a stance of openness and curiosity (Whitebird et al., 2012). MBSR is taught in a structured eight week programme, and incorporates a range of formal practices (e.g., body scan, mindful movement, sitting meditation) and informal practices, which focus on the application of mindfulness to everyday life (Kabat-Zinn, 1990). MBSR sits alongside a range of other approaches (e.g., Acceptance & Commitment Therapy, Mindfulness Based Cognitive Therapy, Dialectical Behaviour Therapy) which share a focus on attending to the present moment and acceptance of experiences, regardless of whether they are pleasant or aversive (Whittingham, 2013). In this report these therapies will be referred to collectively as mindfulness based therapies (MBT).

Increasingly, MBT are used as a mainstream approach to psychological intervention across a range of client groups. MBT have shown beneficial effects for people experiencing mental health conditions such as anxiety, stress, depression, and also physical health conditions such as chronic pain (Gu, Strauss, Bond, & Cavanagh, 2015). The National Institute for Health and Care Excellence (NICE) guidelines recommend mindfulness based cognitive therapy (MBCT) as the treatment of choice for people experiencing recurrent episodes of depression (National Institute for Health and Care Excellence, 2009).

The application of MBT to carer distress is a relatively new development in the caregiving literature. The caregiving role is one that is well known to be associated with anxiety, depression, and stress (Hoppes, Bryce, Hellman, & Finlay, 2012). For example, approximately 25% of family carers of people with dementia have been found to meet diagnostic criteria for clinically significant levels of anxiety (Orgeta, Sterzo & Orrell, 2013). Caregivers have been described as "hidden patients" because of their elevated health risks, which include poor physical health leading to compromised immune function and increased mortality (Whitebird et al., 2012). MBT focus on helping people to develop a different relationship with external stressors, and given their demonstrated effectiveness with other populations they appear well suited to help address the needs of those in a caring role.

Most of the studies that have looked at the impact of MBT on caregivers have focused on parents caring for a child with a disability. Benn, Akiva, Arel, and Roeser (2012) undertook the only randomised controlled study to date of MBT for parents and educators of children with disabilities. They found that parents who received the SMART-in-Education programme (a manualised mindfulness based programme) showed a significant reduction in stress and anxiety at a two month follow-up. Positive effects for parents of children with disabilities have also been shown in a number of smaller studies. These have included reductions in parental stress, using MBSR (Bazzano et al., 2013) and mindfulness-based parent training (Ferraioli & Harris, 2013), improvements on global health outcomes (Ferraioli & Harris, 2013), increased well being (Bazzano et al., 2013), and increased sense of satisfaction with parenting, and improved interactions with their children after delivering a 5 day intensive mindfulness training programme to parents (Singh et al., 2006a). Whittingham (2013) undertook a systematic review of the literature

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on the psychological effects of mindfulness approaches for parents of children with disabilities. Only four papers were included, and the conclusion was that there was 'tentative evidence' that MBT is associated with reductions in parental stress, parental psychological symptoms, child aggression, and child ADHD symptoms.

Only a handful of studies have looked at the effect of MBT on caregivers of adults. Two studies focused on delivering MBSR to caregivers of people with dementia (Hoppes et al., 2012; Whitebird et al., 2012), and one delivered MBT to staff, patients, and family carers in an early psychosis service, modifying a cognitive therapy approach for psychosis to include mindfulness concepts (Moorhead, 2012). These studies showed preliminary evidence for improvements on measures of stress and depression (Whitebird et al., 2012), and increased acceptance and decreased reactivity (Hoppes et al., 2012). In the field of learning disability mindfulness approaches have been trialled with support staff, who are often exposed to high levels of work-related stress. Again, there is preliminary evidence that MBT can have a positive impact on aspects of staff's psychological functioning. Following a seven session mindfulness intervention (developed by the authors), Singh et al. (2006b) found increases in staff satisfaction with work, while other studies used an ACT intervention and found a reduction in the psychological distress of support staff (Noone & Hastings, 2009), particularly in staff who showed higher levels of psychological distress at baseline (Douglas, McConachie, McKenzie, Morris & Walley, 2014). Some studies (using a mindfulness programme developed by the authors) also report that beneficial effects extend to the individuals with learning disability who are being supported, such as increased happiness (Singh et al., 2004), decreased aggression (Singh et al., 2006b), and reduced use of physical restraint (Singh et al., 2009).

3.1.2 Local Context

The local health service provides both health and social care to a small population in a remote geographical region. Because the service is small, there is an expectation that wherever possible, different areas of the service share resources and develop joint initiatives that can benefit multiple patient groups. The psychology team collectively provide services across different areas of health and social care, and whilst individual psychologists sit within their own multi-disciplinary teams, they meet together regularly to review the provision of psychological care across the service. Within this team there has been a recognition that the service would benefit from a more coherent and co-ordinated approach to the delivery of MBT. While individual therapists are providing 'pockets' of MBT in some areas, there has been little co-ordination of how it is delivered or evaluated. A working group was established to address this issue. It envisaged developing a rolling programme of mindfulness groups that could be delivered by a core group of therapists trained to teach mindfulness. Patients, caregivers, and (where appropriate) staff members from any area of the organisation could potentially be referred into the programme.

This delivery approach appeared to hold several advantages within the service context. Firstly, it would allow the resource to be accessed fairly and equitably by different areas of the service. Secondly, it would provide an opportunity to help 'de-stigmatise' people's difficulties, by shifting the focus away from diagnosis, and creating an environment where people with a range of difficulties, and in varied roles, could come together to learn mindfulness skills. Finally, it would allow for more rigorous safeguarding and governance, ensuring that mindfulness teachers had access to appropriate training and supervision, and providing a context for ongoing evaluation and improvement.

An identified difficulty was that currently there is no allocated funding or time for therapists to deliver mindfulness groups. A written proposal was submitted to senior managers in the organisation, who expressed an interest in the concept, but did not commit to allocating any resources. The working group decided to deliver and evaluate a pilot group, as a way to demonstrate its potential usefulness. The group wanted to choose a population that could provide representation from different areas of the service, to highlight its wide applicability. Psychologists in the working group jointly identified that within their own service areas (adult mental health, adult learning disability, adult physical health), carers experienced high levels of stress, with little targeted support or intervention.

A literature review revealed that there has been little research investigating the effects of MBT for family carers of adults with learning disabilities or physical/mental health problems. Furthermore, a qualitative approach has been highlighted as potentially useful in this area, because of the emphasis that MBT places on the subjective experience of participants (Bailie, Kuyken, & Sonnenberg, 2011). The lack of qualitative research has been identified as a gap in the existing literature on MBT and its impact on carers. Chapman et al. (2013) did a systematic review of the use of MBT for carers of people with intellectual disabilities, and highlighted that there is a need for methodologically robust qualitative research "to explore the experiences of those receiving MBT, to identify what they feel the impact of mindfulness has been and to identify which components of mindfulness participants find most useful" (p.188).

3.1.3 Project Aims

The current project therefore aimed to:

1) Deliver a pilot group, offering MBSR to a group of carers across the local health and social service

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2) Evaluate the impact of MBSR on family carers of people with learning disabilities or physical/mental health problems, using a mixed methods approach

3) Contribute a qualitative methodology to the existing literature on the effects of MBT for family carers

4) Use the outcome of the study to make recommendations to the local service about the future provision of MBSR

3.2 Method

3.2.1 Recruitment

A pamphlet advertising the group was disseminated via email to all professionals working in health and social services. Pamphlets were also displayed in the waiting areas of the adult learning disability service, adult mental health service, and adult physical health service. The group was advertised for 'family members who are in a caring role'. Interpretation about who met this criteria was deliberately left fairly flexible, with an awareness that the recruitment process involved a balance between selecting a specific 'population' of carers for research purposes, and meeting the needs of those individuals who were clearly motivated and likely to benefit. People interested in attending the group completed a referral form, and were invited to attend a 'taster session' prior to the formal group commencing. The taster session gave people an opportunity to find out more about mindfulness, and participate in a short meditations, before making a decision about whether to commit to the eight week programme.

3.2.2 Participants

A total of 14 participants started the eight week group programme. Of those, 13 participants completed the programme, and one dropped out after the second session,

stating that she found the meditation process too difficult. Nine participants were female, and four were male. The mean age was 59, with age ranging between 50 to 74 years. Five participants were parents caring for adult children with learning disabilities, five participants were caring for adult family members with mental health problems (either child, spouse, or sibling), one participant was caring for a spouse who had experienced a stroke, and two participants were caring for children with mental health problems.

3.2.3 Procedure

The MBSR programme consisted of eight weekly two hour sessions, and a three hour silent retreat. The group was facilitated by two teachers, who were both trained in mindfulness approaches. Teacher 1 was a clinical psychologist, who had completed an MBSR teacher training qualification with Bangor University. Teacher 2 was a family and systemic psychotherapist, who had completed a 10 month training course in compassion based mindfulness. The eight week programme followed the structure of the University of Bangor's Centre for Mindfulness Research and Practice MBSR programme. Table 5 (below) outlines the content of each session.

Table 5

Session content of the MBSR 8 week programme

Session	Theme	Session Content	Homework
1	Introduction to mindfulness	Group guidelines, Raisin exercise, guided body scan	Guided body scan, mindful routine activity, mindful eating
2	The Present	Guided body scan, awareness of breath meditation	Guided body scan, awareness of breath meditation, pleasant events diary
3	Mindful movement	Awareness of breath meditation, mindful movement, mindful walking	Alternate body scan/mindful movement, awareness of breath meditation, unpleasant events diary
4	Patterns of reactivity to stress	Sitting meditation, discussion about stress, 3 min breathing space	Alternate mindful movement/sitting meditation, 3 step breathing space, record reactions to stress
5	Turning towards difficulty	Sitting meditation, focus on difficult sensations, half way review, explore behavioural responses to difficulties	Sitting meditation, 3 minute breathing space, difficult communications diary
6	Looking after yourself	Sitting meditation, discussion about nourishing/depleting activities and exhaustion funnel	Choose own meditation practice, 3 min breathing space, warning signs of stress
7	Stressful communications	Sitting meditation with less guidance, discussion and role play of stressful communications	Choose own meditation practice, 3 min breathing space
8	Keeping mindfulness alive	Guided body scan, share reflections on group	Continuing guided and non-guided formal meditations, informal practices

In addition to the eight sessions, a three hour silent retreat was provided. This took place the week after the final session. Participants were guided through a range of meditations, and the session took place in silence, in order to give participants exposure to a longer period of mindful practice. In addition to the sessions, participants received a handbook, with written information to supplement each session, and details about homework. The handbook was adapted from the University of Bangor's Centre for

Mindfulness Research and Practice *MBSR Course Workbook.* Participants also received an audio CD, which contained the guided meditations.

3.2.4 Quantitative Evaluation

A literature search was conducted to determine what would be the most appropriate measures to evaluate the outcome of the program. The following measures were selected (Appendix H):

1) *Warwick-Edinburgh Mental Well-being Scale (WEM-WBS)*

The WEM-WBS is a 14 item scale of mental well-being. It focuses on subjective well-being and psychological functioning, with a focus on aspects of positive mental health. Items are answered on a five point likert scale, and summed to give a total score, ranging between 14 and 70 (Stewart-Brown & Janmohamed, 2008). The scale shows good psychometric properties, including evidence of good content validity, and test-retest reliability at both a population level (Tennant et al., 2007) and in clinical settings (Mareswaren, Weich, Powell & Stewart-Brown, 2012). In addition to its sound psychometric properties, the WEM-WBS was chosen for inclusion in the project because it had recently been used in a mental well-being survey of the local population. It therefore offered an interesting opportunity to compare the mental well-being of this group of carers, both before and after intervention, with the local population as a whole. A measure of stress was considered for inclusion in the study (as has been commonly done in other evaluations of MBSR), however the WEM-WBS was favoured because of its focus on the more positive dimensions of mental health.

2) *Cognitive and Affective Mindfulness Scale – Revised (CAMS-R)*

The CAMS-R is a 12 item self-report measure that is designed to capture the multi-faceted conceptualisation of mindfulness. The commonly accepted conceptualisation of

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mindfulness includes four dimensions: ability to regulate attention, an orientation to present experience, awareness of experience, and an attitude of acceptance and non-judgement towards experience (Feldman, Hayes, Kumar, Greeson & Laurenceau, 2007). Participants are asked to rate their ability to use these core skills of mindfulness on a four point likert scale. There is evidence that the measure adequately covers these aspects of a person's experience, as well as demonstrating good convergent validity with other measures (Feldman et al., 2007). While there are a number of mindfulness measures currently available, this one had the advantage of being brief and easy for participants to complete.

3) *Carer Quality of Life (Carer QoL)*

A measure of quality of life for caregivers was included, to assess the potential impact of the MBSR programme on participant's quality of life. The CarerQoL is a recent addition to the measures that are available to assess quality of life in informal carers. It consists of seven dimensions, which describe aspects of burden experienced by carers. These include fulfilment of caregiving, relational problems, mental health problems, problems with combining daily activities, financial problems, social support, and physical health problems. Respondents indicate the extent to which they experience problems in these areas of care, by choosing one of three responses: no, some, a lot. In addition, a visual analogue scale (from 1 to 10) provides a 'happiness score' (Hoefman, van Exel, de Jong, Redekop & Brouwer, 2011). Hoefman, van Exel and Brouwer (2013) examined the construct validity of the Carer QoL, and concluded that it shows good validity properties, and is a useful measure for both informal care research and economic evaluations of health care interventions. This measure was selected in preference to others, firstly because it has been shown to be a popular choice in the caregiving literature in recent years, and secondly because it was brief and easy to complete.

Participants completed the measures prior to the first session, at the end of the final session, and again when they attended the focus group two months later.

3.2.5 Qualitative Evaluation

In addition to the quantitative measures, a follow-up focus group was conducted to find out more about participants' subjective experiences of the group. It was facilitated by the clinical psychologist who delivered the MBSR programme. A qualitative approach has been identified as well suited to the area of mindfulness, because the training is directed at participant's subjective experiences of their thought processes, emotions, and bodily sensations (Bailie et al., 2011). The focus group was conducted two months after completion of the programme. All 13 participants who completed the program were invited to attend. Of those seven attended, including four females and three males.

The focus group followed a semi-structured interview format, with the primary facilitator asking a set of pre-determined questions that were designed to be open-ended and facilitate conversation about participant's experiences of the program. The questions focused on the following areas: what participants found helpful/not helpful about attending the group, their experience of incorporating the ideas/practices into their daily lives, how the group has impacted on their general sense of well-being, mental health, and stress, and how it has impacted on their role as carers, and their relationships with others.

Participants completed a consent form agreeing to the session being video and audio-taped for data analysis purposes (Appendix I). One participant was not willing for the session to be video-taped. For this reason the session was audio-taped only. An assistant psychologist was also present to take written notes, as a back up to the audio-tape.

3.2.6 Qualitative Analysis

Braun and Clarke's (2006) outline of thematic analysis was used to guide the qualitative data process. Thematic analysis is described as "a method for identifying, analysing, and reporting patterns (themes) within data" (Braun & Clarke, 2006, p.6). There are many different ways to approach thematic analysis, depending on the theoretical position of the researcher, and the aims of conducting the analysis (Bailie et al, 2011). In this analysis, the theoretical position taken was that of a theory-driven approach, in which the data was approached with specific questions to address. These questions were based on knowledge of the existing literature on MBSR and its impact on carers, in which a number of key themes were highlighted.

Using the recommendations made by Braun and Clarke (2006), the following phases were undertaken:

Phase 1: Familiarisation with the data

The focus group interview was transcribed into a microsoft word document. Once the transcript was completed the author familiarised herself with the data through repeated re-readings and note taking about initial impressions. The author also kept a reflective journal to record pertinent aspects of the data, and to reflect on her own thought processes during this phase of data interpretation. An assistant psychologist who had previous experience of conducting qualitative research also took part in this process, as one of the quality checks designed to enhance rigour and credibility. She independently familiarised herself with the transcript, and kept reflective notes.

Phase 2: Generating initial codes

Phase 2 began by working systematically through the data to generate a set of initial codes. Coding was done manually, using colours to identify separate codes. This phase was completed together by the two researchers. Disagreements about what constituted a code were discussed until a point of resolution was reached.

Phase 3: Identifying themes

Once the data had been collated into initial codes, the author organised the codes into a set of broader themes. The codes were written on individual pieces of paper, and laid out on a table, in order to help create a visual representation of broader themes. The second researcher also completed this process independently.

Phase 4: Reviewing themes

Both researchers came together to compare and debate the patterns created. Through discussion and debate, agreement developed about the main themes. The themes were further reviewed and refined by consulting with the co-facilitator of the mindfulness group, and the author's supervisor. Themes were 'accepted' if they were supported by several quotes from different participants.

3.2.7 Quality Checks and Reflexivity

As is important in all qualitative research, various steps were taken to ensure that the quality of the analytical process was robust. There is no single set of criteria that researchers agree on for achieving this, however a variety of approaches have been recommended (Braun & Clarke, 2006). In this project a number of these quality checks were used. First, two researchers were involved in the process of coding the data, and identifying themes. Unlike the author, the second researcher had no previous experience with MBT, no knowledge of pre-existing themes in the literature, and had not participated

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in the MBSR group. This allowed a more independent, data-driven view to be taken, in contrast to that of the author who had a more theory-driven approach with associated pre-conceptions about what themes might emerge. Secondly, the author had regular supervision, to help reflect on the process, and highlight elements of subjectivity that were brought to data interpretation. Finally, both the author and second researcher kept a reflective journal, to encourage their own awareness of these issues.

3.3 Results

3.3.1 Quantitative Analysis

Table 6 shows the group means on each measure at baseline, post-intervention, and at two month follow-up.

Table 6

Group means on quantitative measures at baseline, post-intervention, and follow-up

	Baseline	Post-intervention	Follow-up
WEMWBS	40.9	46.0	47.8
CAMS-R	21.1	25.9	28.0
Carer QoL	5.2	8.0	7.6

Figure 7 shows the percentage change in scores from baseline after the MBSR programme, and at two month follow up.
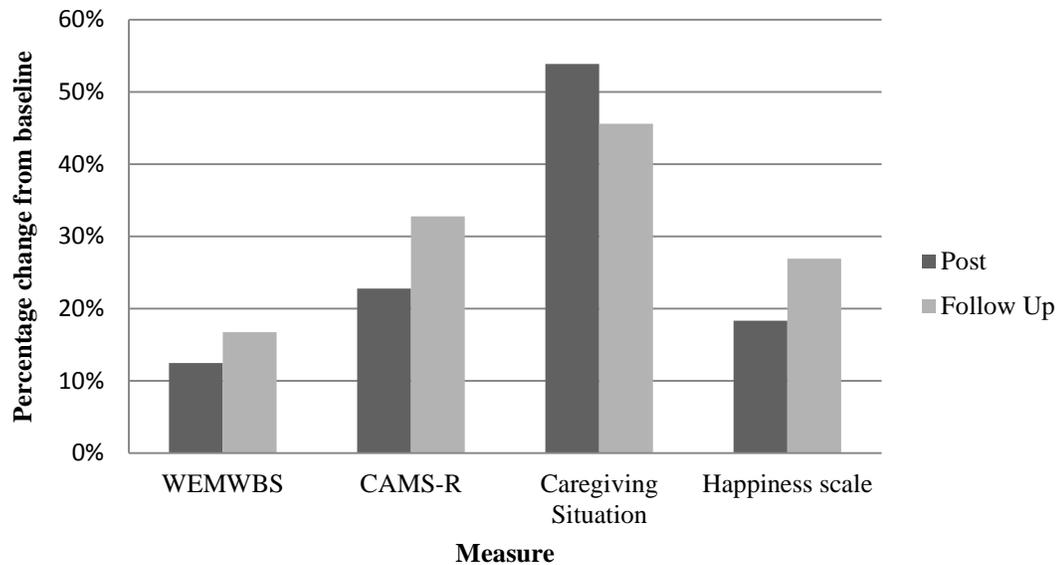
Figure 7 Percentage change from baseline for all measures post intervention and at follow up

A repeated measures ANOVA was conducted on the data to determine whether the MBSR intervention had a significant effect on measures of mental well-being, ability to use core skills of mindfulness, and carer quality of life. There was a significant effect of the programme on participants use of core mindfulness skills, as assessed by the CAMS-R, F $(2,14) = 4.03$, $p < .05$, partial $\eta^2 = .37$.

There was no significant effect of the MBSR programme on mental well-being as assessed by the WEM-WBS, F $(2,14) = 1.62$, $p = .23$, partial $\eta^2 = .19$; carer quality of life as assessed by the CarerQol, F $(2,12) = 2.64$, $p = .11$, partial $\eta^2 = .31$ and CarerQol score F $(2,12) = 3.51$, $p = .06$, partial $\eta^2 = .37$; or happiness scores F $(2,12) = 1.53$, $p = .26$, partial $\eta^2 = .20$.

3.3.2 Themes from Qualitative Analysis

Four themes were identified in the data, three of which had a collection of sub-themes (see Table 7). Where quotes are provided, pseudo names have been given for confidentiality purposes. Line numbers are referenced alongside individual quotes, to denote where they are located in the original transcript (Appendix J).

Table 7

Summary of qualitative analysis themes and sub-themes

Main Themes	Sub-themes
1. The group process	
2. Coping skills	2.1 Relationship with thoughts
	2.2 Present moment awareness
	2.3 Managing stress
3. Doing things differently	3.1 Developing new habits
	3.2 Responsibility for others
4. Relationship skills	4.1 Self-identity within relationships
	4.2 Relationship with others

Theme 1: The group process

One theme to emerge was that the process of attending the group was, in itself, helpful. Michelle explained that she valued the opportunity to have a peaceful space to think and reflect:

"it's nice to have the time, when we came to the sessions...where you weren't interrupted and it was very peaceful where you could think and you could reflect and sort of practice what you were told because there was no distractions and no noise" (14).

She contrasted this with life being chaotic at home, and stated that while it was more difficult to put the ideas into practice at home, the sense of respite that the group provided contributed to making this more possible:

"when you left the course you were then back into the normal hustle and bustle and busyness, so it was possibly harder to bring it into your time, but it was still there...so you could still bring it into your current day" (Michelle, 19).

There was also a sense that coming to the group provided a *legitimate reason* to have a break from the caring role, and that this reflected a step towards new habits of self-care

"I think having a legitimate reason, that's if you need one to step out of your usual perhaps difficult environment and come to somewhere peaceful is a real advantage, breaking away from old habits perhaps" (Michael, 42).

Group members also observed that its helpfulness became more apparent over time. David explained:

"I was very sceptical about the whole idea when it was first mentioned and over the weeks I did gradually buy into it....this guy (referring to himself) was particularly unimpressed to begin with, and actually has found it quite helpful" (138).

Finally, there was an element of having one's own experiences validated by others that appeared to be helpful:

"it's nice to hear other people's versions of what you also experienced or how they felt about the same thing" (Michelle, 54).

Theme 2: Coping Skills

A recurring theme for participants was the extent to which they developed coping skills, which enabled them to feel less stressed.

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2.1 Relationship with Thoughts

A central component of these skills appeared to revolve around participants developing a different relationship with their thoughts. Four of the seven participants described changes in the way that they experienced thoughts. For some, this meant having more control over the content of their thoughts:

"Because..all my problems escalate into something that could be quite uncomfortable, just turn my mind somewhere else and move away, so that's good..and when I've been able to turn my mind to focus on something more positive..I'm learning to think more about my own needs" (Michael, 383)

It also meant learning not to get 'caught up' in thoughts about the future:

"not worrying about what you've got to do tomorrow, next week. Just focus on what you are doing today, right now. And free your mind of all the other worries you might have"

(David, 217).

Kathryn (176) described this process as learning *"how to calm your mind or something"*.

2.2 Present moment awareness

As well as learning to keep the mind more present focused, participants described generally being more aware of present moment experiences, including the breath, the senses, and the self:

'"people get put off by the fact that it's meditation...but it's awareness of yourself and awareness of your senses" (Michelle, 156)

2.3 Managing stress

Participants identified that stressful situations don't occur as often, and that they feel less stressed when problems do occur. Kathryn described her experience of this:

"I think it's been very good, helped us relax, really helped to keep calm and managed to stay calm. Cos when you got some situations you remember what you did at the course just to slow down and breathe and stuff like that, I think it really helps" (8).

Theme 3: Doing things differently

3.1 Developing new habits

Four of the seven participants identified that they have in some way begun to develop different habits since attending the group. These included making time to practice mindfulness at home, planning life better so that it was possible to attend the sessions, slowing down, and knowing when to stop. An interesting reflection was made by Michael, who described feeling more free to play and have fun:

"at work it was mid last week I was accused of being childish...I put a tea towel on my head and I went round pretending to be an arab..it made people laugh, most people, I got the right reaction from most people" (392).

Peter also described the therapeutic value of doing a new activity *"not for any particular reason"* (303), but as Teresa agreed because *"it's just therapeutic"* (337).

3.2 Responsibility for others

Participants also described the beginnings of new relational habits, which revolved around the theme of taking less responsibility, and doing less for other people. Kathryn and Mandy described how the group has affected their habits in the workplace:

"I'm somebody that worries a lot about..what everybody else is doing, and I've managed in

the last few months, well since we started basically, that that's their problem if they're not

doing stuff properly, I'm concentrating on what I do"(Mary, 224)

"I do the same, I try not to get involved, as much as I want to get involved I think that will

give me more work or more stress. I just do my job and go home" (Kathryn, 229).

Theme 4: Relationship Skills

Participants talked about how the group has influenced their relationships with others, and

the way that they view themselves within these relationships.

4.1 Self-identity within relationships

Participants described a theme of beginning to view themselves and their roles within

relationships differently. For example, David reflected that he is beginning to think of

himself as more than just a carer:

"It's made me think more about myself, whereas previously you just thought of yourself as

their carer and you were responsible for everything about the person you were caring for,

whereas now I'm able to step back a little bit and think more about me, and what I need,

and not just what the person you are caring for needs" (256).

Three participants observed that they have been more independent within their marital

relationships. This implied a shift in self-identity, more towards a view of themselves as

people who *deserve* to do what they want. Kathryn described this as

"putting ourselves first (269). *You can go off and do your own thing* (352)*...I've been going*

out quite a bit (laughter) *it's good, leaving him (husband) at home with the kids, but yeah*

I've changed that way, I've left him to do more stuff" (373).

Teresa described this process in terms of experiencing less guilt:

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"you don't feel guilty, most afternoons I go off and sit somewhere and do a bit of crotchet or something and I don't feel, you know I actually sort of, it's good for me, to sit there, I wouldn't possibly of done that before or I'd felt, oh I really should be doing something" (260).

4.2 Relationship with others

Interestingly, only one participant commented directly on the changes that have occurred in her relationship with the person that she cares for. She described a range of positive effects, including feeling closer to her son, and being better able to resist escalating arguments:

"I've learnt to cope now, if you start I'll just think I'm not going to give you any ammunition, I'll just try and calm myself down and let you get on with it and you'll clear it in the end on your own basically" (Mary, 243).

Other participants observed positive benefits in their relationships generally, both at home and at work, identifying that they had more empathy and understanding of other's experiences, and more tolerance in relationships. For example, David (who is married to Teresa) explained that *"I think it's helped the relationship between you and me* (directed at Teresa, 343)..*I think we're a bit more tolerant of each other"* (348). Teresa agreed, saying *"you're still as irritating as you ever were* (laughter) *but I can tolerate it"* (351).

3.4 Discussion

3.4.1 Summary of Results

The aim of the current project was to deliver and evaluate a MBSR programme to family carers of people with learning disabilities or physical/mental health problems. 13 participants completed the eight week program, and the outcome was evaluated using quantitative measures and qualitative analysis. Results indicated that participants showed an improved ability to use core 'skills' of mindfulness. No significant change was found on

measures of mental well-being or carer quality of life, however there was a trend in a positive direction, on both measures. The qualitative evaluation revealed some interesting themes in relation to how the programme was helpful, and changes that it made in participant's lives and relationships. These were best understood within four main themes, which included the group process, use of coping skills, learning to do things differently, and relationship skills.

3.4.2 Relevance to Research Literature

The results of the current study are consistent with the findings of a recent systematic review on the effects of MBSR for family caregivers. The results of the review showed that in most studies there was an improvement in the psychological symptoms of caregivers following MBSR training, including measures of wellbeing, caregiver burden, and ability to use the skills of mindfulness (Li, Yuan & Zhang, 2015). While no qualitative studies were found in the review, those that had a qualitative element showed that participants benefited from MBSR skills and were willing to continue using them.

While the mechanism for how MBSR affects caregivers is not well understood, the research literature suggests a number of different hypotheses, which are relevant to the current study. One of the key components of MBSR is a focus on the present moment experience, in order to reduce emotionally charged thoughts about either the past or the future. Whitebird et al. (2012) suggest that those in a caring role may be particularly prone to thinking about the future, for example anticipating problems, planning, organising, and also to ruminating on stressful incidents from the past. As Bazzano et al. (2013) put it caregivers may be "constantly anticipating future challenges and reliving past traumas" (p.2). One of the helpful mechanisms of MBSR for relieving stress in carers may therefore

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be a greater ability to stay in the present moment. In the current study, this was reflected in the sub-theme of greater present moment awareness.

Another key theme of MBSR involves making a shift from the realm of 'doing' to 'being' mode. Hoppes et al. (2012) describe how caregivers tend to 'double-up on doing', so that in addition to attending to their own needs they also take responsibility for doing tasks for the person they are caring for. For this reason, learning to make a switch from 'doing' to 'being' mode may be particularly difficult, but ultimately more powerful, for people in a caring role. In the current study, the qualitative analysis suggested that this sense of responsibility might extend further than just the person being cared for. Two participants commented on their tendency to take on too much responsibility for the work-load of colleagues, in their places of employment, and reflected on how the MBSR programme has helped them to 'step back' from these responsibilities. Minor, Carlson, Mackenzie, Zernicke & Jones (2006) also highlighted how caring for others can tend to promote over-protectiveness in caregivers.

A related theme that emerged from the qualitative analysis was the importance of recognising and valuing one's own needs. Participants spoke of an increased awareness of their own needs, and a sense of legitimacy about fulfilling them. Minor et al. (2006) suggested that in providing care for others, caregivers tend to neglect their own health and well-being in favour of expending energy in their care-giving role. One could hypothesise that for parents of *adults* with disabilities/health problems, this pattern becomes even more 'fixed' and automatic over time, without the usual developmental processes (e.g., children leaving home at transition into adulthood) that might normally be associated with a period of reflection and readjustment of resources back towards the self. One could speculate that the MBSR group may have helped to facilitate this process of reflection and readjustment,

in the absence of more normal developmental cues. This would be an interesting area to explore in future research.

Finally, Benn et al. (2012) suggest that MBSR is helpful for caregivers because of neural changes that occur in parts of the brain that regulate attention and emotional control. Caring for others clearly requires a high level of focused attention, cognitive flexibility, and emotional regulation by caregivers. Arguably, MBSR can help caregivers to solve problems and respond more skillfully during stressful interactions, by helping to activate these neural pathways.

3.4.3 Implications for Local Service

The current study was conducted as a pilot project, to evaluate the usefulness of offering an ongoing mindfulness service in the local health service. Caregivers were chosen as a defined pilot group, because of an identified need for stress management skills in this population, and a gap in the provision of this intervention. There are a number of outcomes from the current study that have implications for the delivery of future mindfulness programmes within the service.

First, the results of the current project show promise in suggesting that an MBSR programme might be helpful for the psychological well-being of local carers. Interestingly, it is possible to compare the self-reported well-being levels of carers, with those of the local general population. Johnson, Cataroche, Hinshaw and Bridgman (2010) undertook a local population survey of mental well-being, which included the WEM-WBS measure that was used in this study. The mean score for the local general population was 50.53 (S.D = 9.91). In the current study, participants had a mean score of 40.91 before the MBSR programme, which increased to 47.75 at a post-group two month follow-up. This suggests that local carers may experience poorer levels of mental well-being compared to the general

population, but that following MBSR training their mental well-being improves to a comparable level. This has resource implications for the local service. When one considers how much money family carers potentially save the local health and social service annually, acting in ways that foster their mental well-being is arguably an appropriate financial investment. The other noteworthy outcome was the high completion rate. 13 of 14 participants completed the program, which is comparable with other studies of family caregivers. Li et al (2015) identified only a 12% drop-out rate, from 494 caregivers included in their systematic review.

In terms of dissemination, the results of the current project have been incorporated into a proposal for the pilot of a further six month MBSR programme, that extends access to include carers, service users, and staff from across the organisation, and which is subject to further evaluation (Appendix K). Since the project was completed, this proposal has been presented to the service's senior management team, and resources have been allocated for a further six months to undertake this step.

3.5 Critical Appraisal

One of the main strengths of this study was the comprehensive approach taken to evaluation, through the use of both quantitative and qualitative methods. Few published studies in the field have combined both methods, and together with its focus on carers of adults (a group that has received little attention), it potentially makes a valuable contribution to the research literature. However, there were a number of limitations to the study, which warrant further discussion. The study contained only a small number of participants, and for this reason it was difficult to generate sufficient statistical power in the quantitative analysis. Likewise, in the qualitative analysis only a small amount of data was generated by the focus group, and again this limits the conclusions that can be drawn.

There were other methodological weaknesses in the way that the project was conducted. The author acted as both the lead MBSR facilitator, and lead analyst in the qualitative evaluation. This created the potential for bias in the interpretation of the qualitative data. There were other methodological flaws associated with the focus group. Firstly, the person who conducted the focus group was also the facilitator of the MBSR group, and this may have influenced the feedback that participants gave. The focus group was also a self-selected sample, in that it contained only participants from the MBSR group who chose to attend. There was also the potential for a social desirability bias in the focus group, with participants' views perhaps being influenced by the presence of others.

Another weakness of the study was the heterogeneity of the carer group. A decision was made not to impose strict inclusion/exclusion criteria about the carer's relationship to the person being cared for, or the age of the person receiving care. This decision was made on the basis that it was unethical to exclude caregivers from a potentially valuable intervention, particularly when it was unclear whether it would be offered again in the future. However, methodologically this led to a less tightly defined group of carers, which weakened any conclusions that could be drawn.

Finally, the study had a weakness in terms of its original intention within the organisation. One of the aims of the study was to demonstrate the demand for, and effectiveness of an ongoing mindfulness service, that could then be broadened out to include service users and staff from across the organisation. While this project has been effective at demonstrating promising outcomes for carers, it is still not clear to potential funders whether these outcomes will generalise to other service user groups or staff within the organisation. However, it is promising that further temporary resources have now been allocated, to allow for further investigation across a broader population.

The project has also highlighted some organisational barriers to the future implementation of MBSR groups in the service. While it was possible to secure the clinical resources required to deliver a one-off group, and further temporary resources have now been allocated, it remains difficult to secure these resources on a more permanent basis, and this appears to reflect the difficulties of releasing clinical staff from other duties, and the costs associated with training staff to deliver MBSR.

Finally, the project highlights that further research in this area is warranted. Within the local service, there is an interest and arguably a need to support family carers of adults more appropriately, because of the associated social, societal, and financial benefits of developing psychological resilience in this population. A number of recommendations can be made about how to improve on the current study. Future studies require a larger number of participants, and a qualitative methodology that can generate more data, such as individual interviews that are analysed using template analysis. Future studies need to ensure that the delivery of intervention and the qualitative analysis are performed independently. Finally, it is important to acknowledge that this study did not contain a control group, and a larger controlled study that examines carers of adult service users is warranted.

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The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

ii) CAMS-R

THE OHIO STATE UNIVERSITY
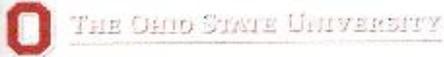
Cognitive and Affective Mindfulness Scale- Revised (CAMS-R)

Please respond to each item by marking one box per row		Rarely/Not at All	Sometimes	Often	Almost Always
CAMS-R1	It is easy for me to concentrate on what I am doing.	1	2	3	4
CAMS-R3	I can tolerate emotional pain.	1	2	3	4
CAMS-R4	I can accept things I cannot change.	1	2	3	4
CAMS-R5	I can usually describe how I feel at the moment in considerable detail.	1	2	3	4
CAMS-R6	I am easily distracted. (R)	4	3	2	1
CAMS-R8	It's easy for me to keep track of my thoughts and feelings.	1	2	3	4
CAMS-R9	I try to notice my thoughts without judging them	1	2	3	4
CAMS-R10	I am able to accept the thoughts and feelings I have.	1	2	3	4
CAMS-R11	I am able to focus on the present moment.	1	2	3	4
CAMS-R12	I am able to pay close attention to one thing for a long period of time.	1	2	3	4

Scoring: Note that 6 is reversed scored. Sum of all values reflect greater mindful qualities.

Your total score: _____

Feldman, G., Hayes, A., Kumar. S., Greeson, J., & Laurenceau, J. P. (2007). Mindfulness and emotion regulation: The development and initial validation of the Cognitive and Affective Mindfulness Scale-Revised (CAMS-R). *Journal of Psychopathology and Behavioral Assessment.* 29(3), 177-190.
Note that original scale was 12 items, but the original items 2 and 7 were deleted as less useful than the remaining 10.

iii) CarerQoL

We would like to form an impression of your caregiving situation. Please tick a box to indicate which description best fits your caregiving situation at the moment.

Please tick only one box per description: 'no', 'some' or 'a lot of'.

I have ☐ ☐ ☐ fulfilment from carrying out my care tasks.

I have ☐ ☐ ☐ relational problems with the care receiver (e.g., he/she is very demanding or behaves differently; we have communication problems).

I have ☐ ☐ ☐ problems with my own mental health (e.g., stress, fear, gloominess, depression, concern about the future).

I have ☐ ☐ ☐ problems combining my care tasks with my own daily activities (e.g. household activities, work, study, family, leisure activities).

I have ☐ ☐ ☐ financial problems because of my care tasks.

I have ☐ ☐ ☐ support with carrying out my care tasks, when I need it (e.g., from family, friends, neighbours, acquaintances).

I have ☐ ☐ ☐ problems with my own physical health (e.g., more often sick, tiredness, physical stress).

How happy do you feel at the moment? Please place a mark on the scale below that indicates how happy you feel at the moment.

completely unhappy — completely happy

0   1   2   3   4   5   6   7   8   9   10

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Video consent form

HEALTH AND SOCIAL SERVICES
A STATES OF GUERNSEY GOVERNMENT DEPARTMENT

Mindfulness Focus Group

Consent Form for Video-Recording

This is the first time we have run a mindfulness stress reduction group for carer's in HSSD. It is important to capture the thoughts, feelings and experiences on this group. To aid this process we hope to video and audio record this session. We then plan to transcribe the comments, and analyse this data for common themes and patterns about the process of going through the programme. We plan to make this into a report which will be distributed

to senior managers within HSSD, as we have further discussions about trying to set up similar ongoing groups in the future. In this report we may use direct quotations, however all names and identities will be anonymous.

The transcripts will be kept securely in a locked filing cabinet and will be destroyed at the end of the write-up. The only people who will have access to the recordings and transcriptions will be people who need it.

Please tick to confirm

I have read the note of explanation above, and have had time to think about it.

□

I consent to video-recordings of this focus group

□

I understand that strict confidentiality will be observed and that recordings will be destroyed after completion of the write-up

□

□

I understand that I can withdraw my consent at any time.

□

I have been given/offered a copy of this consent form.

Date………………………..

Client's name…………………………… Signature……………………………………..

Witness's name……………………… Signature………………………………………

MR

1. Interviewer 1: And usually it's fair to say most people forget it's there after a while and just start

2. talking and it will only be used by us

3. Participant 1: have you tested it?

4. I2: Alright, so um I guess the first question I'd like to ask is just um, just a general one which is

5. finding out a bit about your experience of the program um, yeah what it's been like doing the 8

6. week course and since finishing the 8 week course [pause 5 sec] whose going to be brave

7. enough to [laughter]

8. P1: I think it's been very good, helped us relax, really helped to keep calm and managed to stay

9. calm. Cause when you got some situations you remember what you did at the course just to

10. slow down and breathe and stuff like that, I think it really helps. Practicing and that, I didn't do

11. any practicing, but [laughs]

12. P2: It's nice to have the time aswel

13. I1: Sorry P2

14. P2: that's alright I was just saying it's nice to have the time, when we came to the sessions to

15. have that time where you weren't interrupted and it was very peaceful where we were and

16. you could think and you could reflect and sort of practice what you were told because there

17. was not distractions and no noise

18. I2: yeah

19. P2: and you could just really get into it, whereas when you left the course you were then back

20. into the normal hussle and bussle and busyness, so it was possibly like harder to bring it into

21. your time, but it was still there

22. I2: yep

23. P2: So you could still, if you could bring it into your current day

24. I2: So the time of actually having that group was, was helpful?

25. P2: Yes definitely

26. I2: to take a break from it

27. P2: Absolutely and to have time to peacefully take it all in I think

28. P3: Yes I would agree with that

29. P1:Because you made it part of your plan

30. P2: Yeah

31. P1: so you did it. When you got your free time you don't always, you fill it with something else

32. P2: Hmm, yes you actually made time to do it and it did pay off

33. P4: I found the actual time of it, sort of half past five was a good time, because you didn't have

34. to go home and like myself I work, umm you didn't have to go and sort of rush around and get

35. things sorted, it's your time to finish work and come straight to the course… that was good

36. P1: Because once you get home and get settled down you're not going to come back out again

37. no

38. I2: Yeah- so you didn't get pulled back into that other role

39. P1: so it is good to start early

40. P4: Yeah

41. I2: that's good to know

42. P5: I think having a legitimate reason, that's if.. if you need one to step out of your ususal

43. perhaps difficult environment and come to somewhere peaceful is a real advantage [2.59]

44. breaking away from old habits perhaps

45. I2: Right

46. P5: setting up new good habits

47. I1: Yeah

48. P5: of moving away and of

49. I1: thanks P5

50. P5: so, and to add to that idea a bit, in mindfulness you're learning to live in the moment and

51. be, not have your thoughts centred, moving away from your usual environment is the first step

52. towards that, because for me anyway, that environment consumed me it was taking me

53. P2: And it was also the discussions about things I enjoyed as well, I love talking anyway as you

54. may have noticed, it's nice to hear other people's versions of what you also experienced or

55. how they felt about the same thing and how we all experience different things but ultimately

56. to the good, I think that's fair to say

57. I1: there was a lot of careful listening I noticed, a lot of, so people talking, and showing their

58. experiences was part of it, but also I noticed that other people then were doing some really

59. careful listening about what other people said and that, I think that kind of contributed to the

60. overall feel of the group, that it felt like um, a very respectful space, for me, and that might be

61. different for other people, but that was my experience, that people were really taking on

62. board what other people were at and respecting that space, um and listening to people.

63. P5: I liked the idea that you gave us at the beginning, that ah we were all, or we should treat

64. this group, confidentially, that we didn't have to say anything, and that what we did say would

65. be confidential, um between us, that was really important

66. I1: Yeah

67. P5: For me because it allowed me to feel more relaxed in a social setting where I felt

68. uncomfortable, and doesn't feel comfortable

69. P4: I was a little bit apprehensive when I first walked in because obviously group sessions

70. nobody else obviously knows everybody else, and it um to be the first person to speak or

71. whatever, but I found after that first, sort of halfway through that first session, that anxiety

72. sort of went, and um by the time we got to the session where we had the body on the floor

73. where we had to put the signs on the top I thought that just, everybody just mixed together

74. and it was just like one big group

75. I2: Yeah someone was saying that was a real turning point for them

76. P4: Yeah I think that was for me, I think it was a good mix to get to know people better, maybe

77. you should have done that a little but earlier I thought

78. I2: Hmm

79. P4: because it made everyone

80. Yeah

81. P4: Mix, rather than just come in for the first section and sit and not talk and sit still, no one

82. knew anything

83. I1: Do you think, umm, sorry I'm asking a question

84. I2: No, no, that's fine

85. I1: but do you think if it had been really early on in the 8 week group do you think that people

86. would have felt as comfortable talking about things

87. P1: Yeah, because one of the ladies that I came with didn't go anymore than a week [7.10] she

88. found it really uncomfortable at first but she didn't come to anymore but I think if you had that

89. one first and that one where you went for a walk around the park was much more mixing and

90. then do the sit down ones.

91. I2: Ah ok

92. P1: She found it very uncomfortable just sitting in a circle facing people, it feels very

93. uncomfortable

94. I2: so I mean that relates to another question I was going to ask, whether, there were

95. particular aspects of the group that people found weren't helpful or that they would have

96. changed? So those were some of your thoughts about that

97. P1: She found that very anxiety. I just switched off but some people find that hard

98. I2: so starting off in a more informal

99. I1: It is with strangers

100. P1: yeah with strangers, but the following weeks I said it was better because we went for a

101. walk and that, I think she would have liked that, participating with the charts and the pictures

102. and the talking

103. I2: Hmm

104. P2: I thought it was something you could do as a bonding thing, but not too much just enough

105. that you do work with someone, or that you get to know people a little, rather than just

106. having to sit down, but as they say the body one was great, yeah that was a good one, and

107. then I'm not sure if too early whether we would of all still had the words and what we were

108. trying to say and put down

109. I2: Yep

110. P2: some of those sort of came really from the sessions even the things we'd done

111. P1: Walking around one was quite good, the room

112. P2: It breaks a lot from just sitting down there straight away

113. Yeah

114. I2: Right

115. P1: I think you need to grow into that one

116. P2: Yeah because I found the body scan hard

117. I2: Too hard

118. P2: In the first one, I couldn't concentrate

119. I2: We had lots of debates about whether to start with the body scan, didn't we?

120. I1: Yeah

121. P4 : But that's interesting though that over the course of the 8 weeks, how much easier it got

122. Yeah

123. P4: So maybe it's a good one to start with in the first one

124. P1: Short one was alright though, maybe just a short one

125. P2: So the mindful ones are quite good as well, so the mindfulness of walking, it's a simple

126. thing, but we don't do it, yet, it's you know, it really makes you think, and it's such a simple

127. thing to do,

128. P1: And the noises and smells when we walk down, so I just try and listen to sounds and

129. things

130. P2: The raisin, or the sultana, that was a good one

131. P4: I've never listened to a raisin before, no it was

132. P1: It makes a lot of squeaking noises

133. P4: Trying to explain it to the family when you went home was really strange

134. I1: So I have to ask, has anyone tried listening to a raisin since? [Laughter]

135. P1: I might do that tomorrow, someone's brought some raisins in ... pass it round

136. I2: so has there been any, are they any other comments that people would like to make about

137. what hasn't been helpful about the program? what changes you think might be useful?

138. P6: I don't know if it will help, or if it's a change, but I was very sceptical about the whole idea

139. was first mentioned and over the weeks I did gradually buy into it, so if you're trying to get

140. other people to come on the course, and they're initially somewhat weary of it, you might

141. just say, well this guy was particularly unimpressed

142. I2: Sceptical

143. P6: to begin with, and actually has found it quite helpful

144. I2: great, so you're happy for us to say that in the future,

145. P6: yeah absolutely

146. P1: Maybe explain it a bit more, because on the leaflet, it doesn't really say what it was

147. about, so no one really knew what was going to happen, and they did all think it was going to

148. be like yoga

149. Yeah

150. P1: meditation, no talking

151. I2: so what do you think it would have been good to explain more of, now that you've been

152. through it, how would you explain it to other people? In a pamphlet?

153. P2: that you do a mixture of senses I think

154. P1: I wouldn't call it meditation either

155. No

156. P1: Because people get put off by the fact it's mediation, even though it is, but it's

157. P2: awareness of yourself and awareness of your senses

158. P4: Yeah awareness is a good one

159. P1: Relaxing, how to relax, maybe, using mindfulness

160. I2: Hmm, that's nice

161. P1: But yeah, I thought it was just meditation

162. P3: A different way of coping with things

163. P2: Alternative, how to cope

164. P3: that's the word

165. P2: Yeah, alternative meditation, alternative thought pattern

166. P1: Alternative relaxation classes, in a unique way [laughter]

167. P2: we could write the brochure ourselves at this rate.

168. I1: I think what you're demonstrating is how difficult it is to explain,

169. Yeah

170. I1: it's much easier to show mindfulness and to experience mindfulness, so it is difficult to

171. kind of get people in to start with, to say come and have a go at this and experience it and I

172. think that's the buy in that you were talking about, that once people have experienced it,

173. they start to buy in, but trying to describe it is difficult. [12.00]

174. P2: is difficult

175. I1: It sounds like it's quite tricky, from what you're saying P2

176. P1: How to calm your mind or something, busy

177. I1: Yeah

178. P1: Busy mind, or something

179. P2: Even skeptics even come and do three weeks or four weeks and see if you think

180. differently of it. Give them an alternative, rather than say, oh this ten week course, 'cause I've

181. got to do the whole ten weeks.

182. P1: how many weeks was it? Was it eight?

183. I1: Eight

184. P2: I think it was yeah

185. Yeah

186. P1: Maybe do a taster

187. P2: So maybe do another two or three

188. P4: It did seem like an awful long time, because I had a very small knowledge of mindfulness

189. before I started, but I thought "eight weeks, what are we going to do over eight weeks?" You

190. know how can you sort of carry this on for so long, but there was something that obviously

191. took up every session that we did and it was all very useful so.

192. P3: So you could do taster sessions, one session and then see how many people want to enrol

193. for the whole eight weeks

194. I1 we did do a meet and greet

195. I2: we did do a taster session, yeah, we did a bit of a taster session didn't we

196. I1: that's a good idea, yeah

197. P2: and when you got into the time went really quick and you sort of wanted to carry on

198. really.

199. I1: it did yeah

200. P2: it's a shame it came to an end

201. I2: yeah well I found that the taster session didn't feel like one, it felt like a session because

202. everyone was just naturally ready to go I think

203. I1: that's right yeah

204. P4: I would have liked, just a personal thing of fore-warning about the, when we went walking

205. outside, cause I personally never felt comfortable walking in low light. I know it wasn't

206. exceptionally low light, but it was just that time of year I think.

207. I2: Yeah

208. P4: I did find it beneficial with the smells and taking everything as I was walking around but I

209. was quite eager to get back inside again.

210. I2: Right

211. P4: because I wasn't comfortable. It's just the way I feel about walking around outside at

212. night sort of thing, or low lights, but it erm, not to say I wouldn't have come but I did feel a bit

213. embarrassed that I wanted to sit inside while everybody was outside, but I didn't so.

214. I2: so people said towards the beginning, that urm, there are various ways in which they

215. found the group helpful. How do you think it has helped your general sense of wellbeing?

216. P6: It's helped me to relax more and um, in particular this idea of thinking about the current

217. moment and not worrying about about what you've got to do tomorrow, next week. Just 218.

218. focus on what you are doing today, right now. And er, free your mind of all the other worries

219. you might have. Hasn't worked for me at night I have to say, I still toss and turn, couple of

220. hours at night with a multitude of things flitting through my mind. And I've tried the

221. breathing technique and sometimes it works and I can get back to sleep, but other times I'm

222. still awake two hours later, but yeah it's helped me to focus on the here and now.

223. P4: I've found it helped me do that focus on the here and now, not so much in the caring role

224. but in my working role. I'm somebody that worries a lot about doing things correctly and

225. making sure it's prestine and about what everybody else is doing and I've managed in the last

226. few months, well since we started basically, that that's there problem if they're not doing

227. stuff properly that's their problem, I'm concentrating on what I do. And I still fuss to some

228. extent, but I've learnt to sort of clear my mind of what's not necessary in some ways.

229. P1: I do the same, I try not to get involved, as much as I want to get involved I think "that will

230. give me more work or more stress". I just do my job and go home.

231. P4: So you're more aware of what things might create stress?

232. P1: Yeah as much as you wanna help people it's not your job. So, just focus on what you have

233. to do and get it done.

234. P4: Yeah, I think if I've got time after well then I'll offer to help other people and sort out.

235. P1: I don't I just do my own my own stuff (laughter) I thought that, and then I thought no

236. because then I might have to help again

237. P4: Well yeah

238. P1: I thought no just be selfish and go home (laughter) or go for a walk, make another cup of

239. tea

240. P4: Also in my home environment it's definitely helped me, because I don't get into so many

241. arguments and things with my son that I was getting in before, it was just continual and he's

242. actually commented to me in the last month or so "why won't you argue with me so much

243. mum?" (laughter) "I've learnt to cope now, if you start I'll just think, I'm not going to give you

244. any ammunition, I'll just try and calm myself down and let you get on with it and you'll clear it

245. in the end on your own basically", and um, but for him to actually notice that I wasn't arguing

246. with him anymore was a big change.

247. I2: what's the effect of that been like for you P4?

248. P4: It's been really nice, because before, because my husband's a bit of a sit on the fence

249. type, he'll put his headphones on and read a book, forget anything else that's going on

250. around, so it was always me and my son that was log at heads basically and me asking him to

251. do things and why he wasn't doing it, umm but now I feel I'm much much closer to my son,

252. and my husband's the odd one out now (laughter) but he can cope with that quite well, it

253. doesn't really worry him, but um no definitely relationships got much better.

254. I2: so what are other people's experiences been of the impact of mindfulness on their role

255. and on your role as caring for somebody? Do you think it's impacted on it?

256. P6: It's made me think more about myself, whereas previously you just thought of yourself as

257. their carer and you were responsible for everything about the person you were caring for,

258. whereas now I'm able to step back a little bit and think more about me, and what I need, and

259. not just what the person you are caring for needs.

260. P3: you don't feel guilty, umm most afternoons I go off and sit somewhere and do a bit of

261. crochet or something and I don't feel, you know I actually sort of, it's good for me, to sit

262. there, I wouldn't possibly of done that before or I'd felt, "oh I should really be doing

263. something".

264. I1: Yeah

265. P3: But I think "no, I'm just going to sit here"

266. P1: that's what we all do, sort of selfish

267. P3: Yeah (laughter)

268. P2: well no it's not when you feel better and you can go back and continue the role.

269. P1: it's putting ourselves first and you feel more energetic because you've had, recharged

270. your batteries.

271. P2: Exactly, you've done something

272. P3: something for you

273. P1: so then you don't mind

274. P7: I've had a very stressful time at work, which is just getting a bit er better and so, sort of

275. end of November/ December and so far into the new year and it's been very good because

276. otherwise I would have just found myself the whole time, erm with a great stack of stuff that

277. I'm going to have to do, and you know in fact I'm going to do it and it isn't going to take as

278. long as I think, but if I can just sort of say no, you know I'm doing this at home there's no

279. point in thinking about it.

280. I2: what's it been like for people incorporating it into your lives?

281. P3: probably easier than you would have thought because you think "no it's my time, I'm

282. going to do, you know, for me anyway, I'm going to go and do it, and it's not the end of the

283. world, ok so for the floor might get a bit, but you think, ok I'll do that when it's necessary

284. because I'm going to recharge my batteries, and I think for me that's a big part of the whole

285. thing, that I wouldn't have, or I would have felt guilty.

286. P1: So you've got a dirty house as well?

287. P3: Filthy, it's disgusting (laughter)

288. P2: We've all got dirty houses

289. P1: the kids can drop their clothes on the floor, step over it (laughter)

290. I2: so for you P3, it's been easier incorporating it into your life that you would have thought?

291. P3: yes, your not sort of, I'm not saying I would have felt guilty, but I would have thought to

292. myself, I really should do that,, I really should do. And now I think, it can wait, this is me, cup

293. of tea, just relax, and for you?

294. P6: Yeah I think so, I haven't really incorporated the techniques as such, I don't sit there and

295. do a half hour body scan, or anything of that yelk.

296. P3: it makes you think, differently.

297. P6: It makes you step back and, P3 will tell you I'm anal about our family history, but similarly

298. to her crochet, I don't feel so bad about spending an hour on the computer delving into the

299. family history thinking I should be doing something useful instead.

300. P7: I got a mandalin for Christmas

301. P3: Oh wow

302. I2: Oh how lovely

303. P7: Learning to play that ,I think that's going to be a big of guts as well, yeah because it's not

304. for any particular reason, I'm not thinking of joining a band or urm

305. P3: Mandalin?

306. P7: Yeah

307. P1: It's like a harp thing isn't it?

308. P7: It's, well it's like umm

309. P4: Like a banjo, isn't it? A funny string

310. P7: Yeah it's, a banjo is a sort of you know, like a drum head to it, a mandalin looks like a little

311. guitar, but you know more

312. P3: more like half a cord thing?

313. P7: Um this particular one isn't, it's got a sort of flat soundbox on it and a little guitar with a

314. couple of f holes on it and it's got umm

315. P3: Wow

316. P7: It's quite a short neck, quite a high sound it's got 8 strings which are tuned in pairs in the

317. same way as a violin and if you're good at it, I mean I can't really do this yet, you know you

318. can get a sort of you know vibarato effect in the pairs of strings, you know I mean all I've

319. learnt to play, I got it for Christmas and I made myself a promise that I was going to play old

320. lands eye on it by new years eve (laughter) and put it up on facebook, it's a rudimentary sort

321. of

322. I2: I love the expression you used there P7, you're doing it for no particular reason.

323. P7: Yeah, well I mean my little granddaughter who's not quite two appreciates it (laughter)

324. you know, I've learnt to play twinkle twinkle little star and row your boat on it (laughter) you

325. know she'll see it and will pick up the pleptrum and put it in my hand

326. Aww

327. P7: so it will give me a little …

328. I2: that's sweet

329. I1: It reminds me of that kind of idea of playing for plays sake

330. I2: Yeah

331. I1: I think we talked about earlier on in the group, like a beginners mind or child's mind idea

332. that mindfulness can help us with, so, you know rather than playing for an outcome, just

333. playing for the intrinsic quality

334. P7: Yeah

335. I1: of playing, it's a lovely idea

336. P7: I mean I have to say I've got no real talent for music or anything like that

337. P3: It's just therapeutic,

338. P2:it's the same as crocheting?

339. P3: well for me it is yeah

340. I2: So we've touched on this question a little bit already but I'm interested in how

341. mindfulness has helped with the relationships that you have with other people, with the

342. people that you care for?

343. P6: I think it's helped the relationship between you and me [*directed at wife*] I'm not sure

344. P3: has it? (laughter)

345. P6: This is where I leave

346. P1: You've got a sense of humour

347. P3: we have got a sense of humour

348. P6: I think we're a bit more tolerant of each other

349. P1: He's got a better sense of humour now aint he

350. P6: It's err, I'm not sure it's changed the relationship

351. P3: No you're still as irritating as you ever were (laughter) but I can tolerate it

352. P1: you can go off and do your own thing

353. P3: Definitely

354. P1: You've not got to be together in one room, I do the same with my husband, he watches

355. something downstairs I go off somewhere else so we don't really spend much time together

356. (laughter) that sounds a bit mean doesn't it,

357. P4: My husband always plugged into his headphones with a book but he says I watch the telly

358. but I watch the telly

359. P3: Who says you've got to, it's quality not quantity

360. P1: Yeah, who says you've got to spend all your time

361. I2: And P1 is that something that's changed as a result of the group? Or is that?

362. P1: I think it's changed a bit more yeah

363. P3: More tolerant

364. P1: I've hardly seen him at all (laughter) I've been going to the cinema, I've been going places

365. without him with friends and other people

366. P3: What you want to do

367. P1: Yeah, he doesn't want to watch that film so, I saw the Steven Hawkins film on Friday it's

368. brilliant, you need tissues

369. I2: yeah it does

370. P4: the two girls at work went to see it cried right from the start

371. P1: very good, that's the whole point though, thinking about yourself. He doesn't wanna go

372. see that, so my olderson came with me cause he's into computers and all that, cause he is

373. very technical that guy eh, it's very good, yeah so I've been going out quite a bit (laughter) it's

374. good, leaving him at home with the kids, but yeah I've changed that way, I've left him to do

375. more stuff.

376. P5: it's helped me to change my focus when there's something troubling me I forget about

377. that and turn my mind somewhere else

378. I2: right

379. P5: Whether it's the television or whatever

380. I2: Yeah

381. P5: So umm, in that way it helps relationships I guess at home and at work

382. I2: right

383. P5: because, ah rather than focusing, all my problems escalate into something that could be

384. quite uncomfortable, just turn my mind somewhere else and move away, so that's good. And

385. when I've been able to do that, umm, I've been able to turn my mind to something more

386. positive and focus on that for me, so I'm learning to think more about my own needs, so

387. that's been, coming to the mindfulness has been, the beginning for me I think or allowing me

388. to begin, helping me to begin

389. P3: that's lovely

390. I2: that is lovely

391. P5: So, er, that's good. Something that just popped into my mind, its not pertinent to this

392. conversation perhaps, but er talking about having a child's mind, at work it was mid last week

393. I was accused of being childish, I would rather it be child like, but at work I put a tea towel on

394. my head and I went round pretending to be an arab (laughter) and err, I was accused of being

395. childish. It made people laugh, most people, I got the right reaction from most people

396. I2: so it was a playful thing to do

397. P5: one person in particular took offense

398. P1: they all got their opinion eh

399. P4: probably didn't have a tea towel to follow you

400. P5: perhaps. After that I was in pound world, smith street and some childrens toy thingy with

401. a white mask and paint .

TAPE ENDS

Service development proposal

Proposal for the Development of a Mindfulness Service to Enhance Patient , Staff, and Carer Well-being

Current HSSD Context

Current HSSD strategies highlight the objective of promoting health and well-being across the Guernsey community. HSSD is under pressure to deliver evidence-based interventions cost-effectively, in order to meet this objective. This proposal aims to meet this need, in a creative and innovative way.

The recent Mental Health and Wellbeing Strategy estimates that the current cost of mental health (MH) problems in Guernsey is approximately 100 million pounds per annum. In addition to treating clinical populations with evidence based interventions, mental health promotion and prevention is seen as key to reducing the associated financial and societal costs. 'Fewer people are likely to develop mental health problems in populations with high levels of mental wellbeing'(p.3, Mental Health &Wellbeing Report, 2012).

In addition to prioritizing MH prevention, the strategy highlights other key areas, which include challenging stigma and discrimination, addressing the needs of carers, and providing 'safe and effective' services that are based on evidence-based treatments and strong governance processes. Addressing the needs of carers has also been prioritized in the Supported Living & Aging Well Strategy, and the Disability & Inclusion Strategy, because of concerns about an aging population, and the significant role that informal carers play in supporting people with health needs in Guernsey.

What is Mindfulness?

Mindfulness is a skill that can help to promote people's wellbeing and psychological resilience to difficult life events. In mindfulness approaches, people are taught to develop a particular type of attention, which includes a focus on the present moment, with non-judgemental awareness and acceptance of the experience (Williams & Penman, 2011). Mindfulness is most commonly taught in a structured 8 week group program.

How is Mindfulness Relevant to HSSD?

There is a well established evidence base for mindfulness therapies (MT) in the treatment of both physical and mental health problems, including anxiety,

depression, and stress, and the psychological impact of physical health conditions such as chronic pain and cancer (Gu et al, 2015). MT has also been shown to enhance mental well-being in non-clinical populations, including carer and staff populations (Benn et al, 2012).

The current provision of MT in HSSD is patchy and poorly co-ordinated. Its accessibility is limited, and there is a lack of governance procedures around the supervision and training of those implementing it. Within existing HSSD resources, two staff have recently been trained to deliver MT. A pilot group was subsequently conducted in 2014, with 14 carers of HSSD service users. Outcome data at post-group and two month follow-up showed increased levels of mental well-being, and reduced levels of 'caregiver burden'. The program also demonstrated a high completion rate, with 13 of 14 participants completing the 8 week program. A two month follow-up focus group was conducted to obtain participant's views of the program. All six participants in the focus group reported that they continued to use mindfulness skills in their daily lives, and described a range of ongoing benefits.

Occupational Health in HSSD have recently commissioned a series of introductory mindfulness sessions and an 8 week group program for staff, from a private mindfulness provider. This suggests a demand for MT that is not currently being met within HSSD.

The Current Proposal

Stage 1

- Stage 1 of the proposal is to pilot the provision of a mindfulness based group program, for an initial period of 6 months.
- The program would be accessible to service users, staff, and carers from across all areas of HSSD. The program would help to target clinical populations that are known to benefit from MT e.g., people with anxiety disorders, depression, chronic pain, and other physical health conditions, as well as non-clinical populations who can experience high levels of emotional stress e.g., carers, staff within HSSD. Delivering the program across both staff and service users has the important function of helping to de-stigmatise MH problems, and allowing HSSD staff to model proactive ways of enhancing well-being.
- In a 6 month period 6 groups would be conducted. 10-15 participants per group = 60-90 participants.
- The pilot program would be evaluated using a range of outcome measures, and would aim to clarify the demand for the program, and evidence of its effectiveness.

- Stage 1 could also serve as a preliminary training phase. Staff identified as future trainers would have the opportunity to participate in the program, which is the first requirement for obtaining a formal mindfulness teaching qualification.

Stage 2

- Depending on the outcome of the pilot program, it is proposed that a longer-term framework be considered, with a focus on:

  - The delivery of a rolling program of MT groups, accessible to service users, staff and carers from across HSSD.
  - Expansion of the program, to target the wider Guernsey community, in accordance with the strategic objective of promoting health and well-being for all Islanders.
  - Funding for ongoing supervision and training of a pool of identified professionals, who could deliver the MT program.
  - Agreement from relevant managers that identified staff have time allocated in their JDFs to deliver the MT program.
  - Agreement from relevant managers that staff would only deliver group based MT within the framework, to ensure that they operate within an appropriate governance structure.

Cost/Resource Implications

Stage 1 –

- It is proposed that stage 1 is achieved within existing resources, by allowing the secondment of a qualified MT trainer to implement the pilot program at 0.4FTE.
- Negotiation from other parts of the service to assist in backfilling this position, if required.
- Assistant Psychologist (from existing resources) to assist with administration, data collection, and data evaluation.

Stage 2 –

Propose 2 options (see Appendix for details)

1) Establishment of permanent 0.4 FTE. Backfill to be negotiated from within the service.

2) Train a team of staff, with time allocated in JDFs to conduct specified number of groups per year.

Potential Benefits to HSSD

- Provision of an ongoing group MT program which is:
  - Focused on the promotion of well-being, in line with HSSD objectives
  - Evidence-based
  - Cost-efficient
  - Shown to be effective for a wide range of physical and mental health problems
  - Shown to be effective for people in a caring role
  - De-stigmatising for MH service users
  - Focused on the emotional wellbeing of HSSD staff
  - Well co-ordinated, with emphasis on a clinical governance and supervision framework
  - Complements recent developments in the Education Department, who are nearing completion of a mindfulness framework to encompass MT for staff and students, across Guernsey schools.

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4.0 Critical Appraisal of the Research Report

Word Count: 1,721

4.1 Origins of the Study

I can trace the origins of this study back to a key discussion that I had with my clinical supervisor. At that time my clinical experience within learning disability services had been mainly confined to talking therapy with service users and their families. In my new post I was required to take a more active role in the development of positive behavioural (PBS) services, and I felt daunted by the challenge of 'starting at the beginning' of a journey to shape local services in this way. I expressed concern to my supervisor that I didn't know what a good quality service residential service should look like, and he responded by saying that I would only know once I'd created one myself. That comment stayed in my mind, and served to intrigue and motivate me. I began to do some more reading in the area, and held further discussions with my new PBS colleagues.

As a team we were acutely aware of the lack of basic building blocks within the service. There was little offered in the way of staff training, few structures to support staff's reflective practice, and little formalised paperwork within community homes. As a service we had a high number of out-of-area placements for people with challenging behaviour or mental health needs, at a time when the Winterbourne View report had just been published (Bubb, 2014). Both the Winterbourne View report and an earlier report published by Mansell (2007) emphasised the need for people with challenging behaviour to be supported by good quality services that were close to home, and the need to build capacity in the local community through workforce training and access to specialist professional support. A key aim of the wider organisation was to repatriate people in out-of-area placements, but we knew that we needed to improve local services first. So where was the best place to start? As a team attempting to answer this question we found ourselves increasingly drawn to active support (AS) for a number of reasons. Firstly, it is considered to be an important

component in preventing challenging behaviour (Jones et al., 2013), and improving quality of life (Mansell & Beadle-Brown, 2005) which were consistent with two key objectives of the PBS team. We were also aware that while the service did not currently experience high levels of challenging behaviour compared to many other UK catchment areas, there did appear to be high levels of disengagement and a 'hotel minding' approach to residential care. AS was also appealing because it offered structured staff training, alongside a range of planning and organisational tools. It also gave us a framework to start introducing reflective practice amongst staff teams, a key feature of good quality services (Mansell, 2007).

My interest in the relationship building component of AS developed from my own clinical experiences as a therapist within learning disability services, and a recognition that the role of rapport and relationship was critical to good quality of life outcomes for people with learning disabilities in this context. While reading the PBS literature, and the recent emphasis on the role of rapport (McLaughlin & Carr, 2005) I was intrigued by the parallel between this and psychotherapeutic relationships, in which the therapist-client relationship is known to be an important variable in effective psychotherapy outcomes (Roth & Fonagy, 2006).

4.2 Creating the Context for Change

In retrospect one of my key learning points was the importance of creating a context in which change could occur. My supervisor emphasised the need to get 'buy in' from all levels of the organisation before the project commenced, and this became a public relations exercise in making others feel as enthusiastic about AS as we did. We were careful to consult with, and inform staff at all levels of the organisation about the project, and to provide regular and timely updates about progress and outcomes. We also made use of the local media, holding an initial training workshop that obtained local radio and newspaper

coverage. This helped to create momentum and motivation in staff from across the service, and a sense of unity and value in what we were setting out to achieve together.

4.3 Delivering the Intervention

This was my first experience of leading a research team, and I learnt a lot from being in this role. I am aware that a major weakness of the study was that data collection was conducted by people who were not independent of, or blind, to treatment conditions. This is an important source of potential bias in the study that needs to be acknowledged. It reflects the difficulties of conducting research in a real-life clinical setting, which was compounded by the small size of the service. I had ideally hoped to have independent observers, but I was unable to obtain the staff resources needed to achieve this. This meant that I was required to undertake different roles simultaneously, that of research co-ordinator, coach, observer, and data analyst. I felt that this may have had an unsettling effect on staff in the homes, and more importantly might have influenced their behaviour as they were observed.

4.4 Data Management

The study has taught me a great deal about various aspects of data management. In retrospect, I would have planned the data collection phase more carefully, to ensure a more even spread of observation sessions across time, and to utilise resources more effectively. Data collection continued throughout the coaching phase of the intervention, and it was only once I got to the data analysis stage that I realised that this data did not clearly belong to either the baseline or intervention phase. A decision was made to exclude this data, and in hindsight these observation hours could have been better utilised elsewhere. Time was also lost entering large amounts of raw data onto an excel spreadsheet, and created confusion when the data was re-evaluated some time later. In retrospect, percentages for

each observation session should have been calculated at the beginning, and only this data entered onto the excel spreadsheet.

4.5 Study Limitations and Future Directions

There are a number of study limitations, which need to be highlighted. Firstly, because of significant gaps in the collection of baseline data there was no overlap between intervention in one service and baseline in others. This limited the extent to which experimental control could be demonstrated, and in essence the study design became one of a series of single case experiments rather than the stronger methodology of a multiple baseline design, which had been the intention. Another significant weakness of the study was that those who collected the observational data were not blind to the intervention status of the house, nor independent of the overall research process. Clearly, this increases the possibility of a bias in the way that data was coded. Another consequence of operating within a small service (in a confined geographical region) was the potential for treatment to be 'contaminated' across environments, by a high cross-over of staff between areas who had strong professional and personal links. Because of the small distances between community homes (no further than a 10 minute drive) staff were often substituted across homes for different shifts, at short notice. In practical terms, this meant that it was difficult to contain the treatment effects to one community home at a time.

Another potential criticism of the study was whether the video reflective practice focused sufficiently on relationship building, and indeed whether it was different enough from standard AS coaching. Preliminary results from the Interaction Checklist (IC) also indicated that the checklist itself warrants refinement, with some of the codes reflecting the quality of staff interactions more helpfully than others. Both of these limitations are explored further in the discussion section of the research report.

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In terms of future research, it would be helpful to expand on this preliminary piece of research, which has begun to look more systematically at how staff can build reflective and enabling relationships with the people that they support. In the future it would be useful to trial the IC in another setting, perhaps where there are higher levels of challenging behaviour, greater evidence of restrictive practices, and lower levels of initial engagement at baseline. In this project there was evidence that passive inattention was the most common negative interaction that staff engaged in, with many of the remaining six negative codes recorded infrequently. Depending on the outcome of follow-up studies in different settings, it would be useful to refine the checklist, by modifying or removing codes that continued to show infrequent use. It would also be interesting to collate quantitative data collected from the IC with further qualitative research, to see how staff's own reflections of relationship building relate to data collected from the checklist. The video reflective practice would also benefit from further development and refinement, and this is also discussed further in the main research report.

4.6 Summary Reflections

In terms of my own personal and professional development there are many positive skills that I have learned as a result of conducting this study. I have developed practical clinical skills in the delivery of AS training and coaching, and I feel more confident in my ability to help staff at all levels of the organisation to reflect on their relationships with service users and to implement the practical aspects of AS. I have developed skills in planning a comprehensive piece of research, promoting research within the organisation, co-ordinating a research team, collecting observational data in a service setting, and collating and analysing large quantities of data. I can reflect back on the original conversation that I had with my supervisor, in which I sought to clarify what a 'good

quality' service looks like, and know that as a result of this study I have a far better idea of what one should look like, and how to achieve it. At the beginning of this project, my hazy conception of a 'good quality' service was one in which service users spent a significant amount of time doing activities in the community, while staff developed comprehensive paperwork that operationalised and defined the individual needs of service users. Now I know that while these elements of service delivery are important, ultimately service users and staff doing the 'little things' together, caring about each other, and having fun in the process is what really matters. I have had the privilege of seeing pleasure on the faces of both service users and staff, as they share 'good moments' together. For all the wonderful staff and service users who have been involved in this project I hope that there are many more 'good moments' to come.

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