



Jahoda, A., Melville, C.A., Pert, C., Cooper, S.-A., Lynn, H., Williams, C., and Davidson, C. (2015) A feasibility study of behavioural activation for depressive symptoms in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 59(11), pp. 1010-1021.

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

This is the peer reviewed version of the following article: Jahoda, A., Melville, C.A., Pert, C., Cooper, S.-A., Lynn, H., Williams, C., and Davidson, C. (2015) A feasibility study of behavioural activation for depressive symptoms in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 59(11), pp. 1010-1021.(doi:[10.1111/jir.12175](https://doi.org/10.1111/jir.12175)) This article may be used for non-commercial purposes in accordance with [Wiley Terms and Conditions for Self-Archiving](#).

<http://eprints.gla.ac.uk/100810/>

Deposited on: 20 August 2015

<http://eprints.gla.ac.uk>

**Title: A FEASIBILITY STUDY OF BEHAVIOURAL ACTIVATION FOR
DEPRESSIVE SYMPTOMS IN ADULTS WITH INTELLECTUAL
DISABILITIES**

Abstract

Background:

Important work has been carried out adapting Cognitive Behavioural Therapy (CBT) for people with intellectual disabilities. However, there is a lack of alternative psychological therapies available for people with intellectual disabilities and emotional difficulties. Behavioural Activation for depression is less reliant on verbal communication and focuses on increasing purposeful activity and reducing avoidance.

Method

This feasibility study involved the development and piloting of an adapted manual of behavioural activation for people with intellectual disabilities. The intervention consisted of 10 -12 sessions and a key adaptation was that the therapist worked with the clients alongside a significant other in their life, either a paid carer or family member. Baseline, post intervention (3 months after entering the study) and 6 month quantitative follow-up data were obtained. Primary outcome data were gathered, concerning depressive symptoms, participants' levels of activity and general well-being.

Results

Twenty three adults with intellectual disabilities with symptoms of depression were recruited from specialist health services. In terms of acceptability the behavioural activation intervention was well received and only two individuals dropped out, with

Behavioural Activation for depressive symptoms

a further two lost to follow-up. The main measures of depression appeared to be sensitive to change. Pre to post intervention data showed a significant reduction in self-report of depressive symptoms with a strong effect size ($r = .78$), that was maintained at follow-up ($r = .86$). Positive change was also obtained for informant reports of depressive symptoms from pre to post intervention, with a strong effect size ($r = .7$). Once again, this positive change was maintained at follow-up ($r = .72$).

Conclusions

The study suggested that behavioural activation may be a feasible and worthwhile approach to tackling depression in people with intellectual disabilities. However, a randomised controlled trial would be required to establish its effectiveness, with more sensitive measurement of change in activity.

Introduction

The epidemiological evidence suggests that depression is at least as prevalent amongst individuals with intellectual disabilities as amongst their non-disabled peers, with an estimated point prevalence of 5% (Cooper et al, 2007). Depression is longer lasting and perhaps more resistant to change amongst people with intellectual disabilities, with 15% of a British cohort with intellectual disabilities meeting the criteria for chronic depression as compared to 3% in the general population (Collishaw, Maughan and Pickles, 2004). One possible explanation is that the particular social circumstances and life experience of people with intellectual disabilities, including being socially marginalised and facing stigma, contribute to a heightened risk of depression (Jahoda et al, 2006). Moreover, such individuals may often lack the social support and personal resources that help to provide resilience from depression (Lunsky and Benson, 2001). This paper reports on an open trial of behavioural activation therapy for individuals with intellectual disability and depressive symptoms. A key component of behavioural activation is to increase the client's level of purposeful activity (Lejuez et al, 2011), often markedly absent in the lives of people with intellectual disabilities.

Considerable work has been carried out to develop and study the efficacy of psychosocial interventions for depression in the general population (Butlet et al, 2006; Cuijpers et al, 2008) but only limited evidence is available for people with intellectual disabilities. Recent efforts focused on the adaptation of cognitive behavioural treatment (CBT) models have shown promise (McCabe, McGillivray and Newton, 2006; McGillivray, McCabe and Kershaw, 2008). However, for many individuals with intellectual disabilities, CBT involves excessive cognitive and communicative

Behavioural Activation for depressive symptoms

demands (Dagnan and Chadwick, 2000; Sams et al, 2006; Willner, 2006) and is therefore not accessible. Aside from ability, different approaches are likely to prove more suitable or engaging for different clients, as is assumed in the general population. Consequently, increasing the range of available therapeutic interventions with proven efficacy would offer choice to clients with intellectual disabilities and their families or support persons, something that is noticeably absent at present.

A recent meta-analysis of studies with the general population found that in the management of depression, behavioural activation therapy is as effective as CBT (Ekers et al, 2008). Behavioural activation treatments (Jacobson et al, 2006; Dimidjian et al, 2006) are based on behavioural theory of depression, where withdrawal from adaptive and positive behaviour contributes to low mood. The aim is to identify the triggers that lead to the avoidance of healthy behaviours and break the depressive cycle. A somewhat simplified approach was developed by Lejeuz et al, (2001), which had the more straightforward aim of increasing overt behaviours that are likely to bring the individual into contact with positive environmental contingencies, with a corresponding improvement in mood, thoughts, and overall well-being. This was based on matching law (Lejeuz et al, 2001) which proposes that depressive symptoms can be reduced by shifting the balance of reinforcement from 'depressive' symptoms to 'healthy' non-depressed behaviours. This approach still takes account of the function of the depressed individual's behaviour in the broader context of their life. The aim is not merely to increase activity but to ensure that the activities are purposeful and motivating for the individual concerned. Given the chronicity of depression experienced by people with intellectual disabilities (Collishaw, Maughan and Pickles, 2004) a focus on lifestyle changes that help to maintain improvement in

Behavioural Activation for depressive symptoms

mood could prove effective. Evidence from interventions that have successfully increased the activity levels of people with intellectual disabilities suggest corresponding improvements in mood (Stancliffe et al, 2010).

This study set out to adapt a manualised version of Behavioural Activation for people with an intellectual disability and to examine the feasibility of the approach in an open trial. An update of the guidelines for complex interventions for the Medical Research Council in the UK (Craig et al, 2008), emphasised the importance of early phase development work to underpin large scale studies by dealing with key conceptual and practical questions. The following issues were tackled in this study:

i) Recruitment: People with intellectual disabilities rarely refer themselves for psychological help. Consequently, those who are withdrawn and depressed but do not challenge others may be overlooked. Individuals' depressive symptoms can also be masked by other emotional and inter-personal problems like anger or anxiety (Moss et al, 2000). Hence, it was necessary to establish whether it was possible to identify and recruit people with intellectual disabilities and depressive symptoms in sufficient numbers; ii) Acceptability and compliance: Given the strictly voluntary nature of the participants' engagement in therapy, as governed by ethics, it was important to establish if the therapy was acceptable to the participants and whether they remained engaged in the intervention. iii) Retention: Due to the voluntary nature of the participants' involvement in the study, a further question was whether participants would be prepared to meet with the researcher after a follow-up period. iv) Sensitivity of primary outcome measure: The aim was to examine whether the measures of depression were sensitive to change, along with a measure of general well-being, and

Behavioural Activation for depressive symptoms

v) Measuring key mechanisms of change: A final question was whether change in levels of activity, the predicted mechanism of therapeutic change, could be charted.

Method

Participants

Participants were recruited over a 14 month period from specialist intellectual disability services in two NHS Health Boards in Scotland. The criteria for participating in the study were that the participants should be identified by clinicians as having intellectual disabilities, currently experiencing depressive symptoms, be over 18 years of age and be receiving support from a family member or paid carer who had been working with them for at least 6 months and was able to attend the therapy sessions.

Design

Participants were followed up for six months after entering the study and measures were taken at three time points: Time 1- at baseline prior to starting the intervention; Time 2- upon completion of the intervention (three months); Time 3- follow up (six months).

Measures

Depressive symptoms

To investigate improvement in depressive symptoms the following measures were completed. Where possible, the participants completed the self-report measures but for those with more significant impairments third party reports from family members or support workers were used to chart change.

Behavioural Activation for depressive symptoms

Self-rating: *The Glasgow Depression Scale for People with Learning Disabilities* (GDS-LD; Cuthill et al, 2003): This is a 20 item self rating scale that requires respondents to indicate how often a particular symptom has occurred using a 3 point scale (never/sometimes/always), during the previous week. The GDS-LD has good content and discriminant validity. The correlation between the GDS and the Beck Depression Inventory-II (Beck, Steer and Brown, 1996), when the two measures were completed by non-disabled individuals, indicates high criterion validity ($r = .94$, $P < 0.001$). However, the Beck Depression Inventory-II, does not use language or a response format that is accessible to most individuals with intellectual disabilities. The GDS-LD also has high short-term test-re-test reliability and high internal consistency (Cronbach's $\alpha = .90$; $n = 38$).

Carer rating: *Intellectual Disabilities Depression Scale* (IDDS; Evan et al, 1999): This is a 38 item behavioural checklist derived from DSM-III-R criteria, designed to measure the frequency of identified depressive behaviours within a four week period. The IDDS has acceptable inter-rater agreement, and findings from the open trial have shown a high level of correlation between self-report on the GDS and carer report on the IDDS ($r = .77$, $p < .001$).

Activity measures

To investigate if it was possible to detect any increase in activity, the following measures were completed jointly with the participant with an intellectual disability and their support person. To be consistent with the therapeutic approach, the aim was

Behavioural Activation for depressive symptoms

to attempt to chart change across different life domains and two measures were selected for this purpose.

Index of Community Involvement (ICI; Raynes, Sumpton, and Pettipher, 1989a): This scale provides a measure of participation in social and community based activities during the previous 4 weeks. The ICI asks participants about their engagement in 15 community activities, ranging from going to the pub, taking part in sporting activities and using public transport. The ICI has demonstrated good inter-rater agreement of 95% and good internal consistency (Cronbach's alpha = .79).

Index of Participation in Domestic Life (IPDL; Raynes, Sumpton, and Pettipher, 1989b): This scale measures participation in 13 household tasks during the previous 4 weeks. The items covered include gardening, preparing meals and cleaning bedrooms. The IPDL has been reported to have good inter-rater agreement (95% and 97%) and good internal consistency (Cronbach's alpha = .89).

General Well-Being

The support persons completed the following measures concerning the general well-being of the participants.

HONOS-LD (Roy *et al.* 2002): HONOS-LD was developed as an outcome measure for use by people with intellectual disabilities and mental ill-health. To complete the HONOS-LD, raters select a score from 0-4 in 18 domains. Lower scores reflect better functioning and well-being. In the original development work, the inter-rater reliability of HONOS-LD (Pearson's product moment correlation) was good, when

Behavioural Activation for depressive symptoms

completed by clinicians providing a service to the person with intellectual disabilities. HONOS-LD was also demonstrated to be sensitive to change over a three-month follow-up period (Roy *et al.* 2002). These findings suggest that HONOS-LD is a robust outcome measure for use in research.

Development and delivery of the Behavioural Activation Manualised Therapy

Although behavioural activation begins with the advantage that it is less reliant than CBT on verbal communication to access emotions and thoughts, the therapeutic intervention still has to be carefully adapted to take account of the cognitive and communicative difficulties of these individuals and their particular life circumstances. A key aspect of the behavioural activation intervention concerns lifestyle change, raising the question of whether people with intellectual disabilities and depression have sufficient self-determination to make and maintain required changes in their lives (Jahoda *et al.*, 2009). One of the main changes made to the adapted behavioural activation approach was to deliver the intervention to both the individual with intellectual disabilities and a significant other in their lives. The aim was to take advantage of existing or natural supports in the person's life to help ensure that change actually takes place. Including a support person also makes the approach accessible to those who can only engage in the therapeutic process with assistance.

A series of three case studies were completed to help pilot and adapt the manual before it was finalised. This session plan was based on the 'brief' behavioural activation treatment developed by Lejeuz *et al.* (2001). None of these case studies were included in the feasibility study data presented in the Results section. The case studies helped with the development of session content, including the exercises to

Behavioural Activation for depressive symptoms

build up a picture of the participants' activity and a template for the formulation booklets. Moreover, the case studies also helped to shape the therapy process, including the pacing of sessions and determining the number of meetings required to complete the assessment phase and to familiarise the clients and supporters with the therapy materials.

The intervention was delivered by a research psychologist with prior clinical experience of delivering psychological interventions, under supervision from a clinical psychologist with longstanding experience of delivering psychological therapies to people with an intellectual disability and training therapists. The therapist received weekly face-to-face supervision, and the structured notes the therapist wrote up after each therapy session were discussed.

Therapy sessions were held weekly or fortnightly in the clients' homes. Clients would have been offered the option to meet elsewhere if they had wished to so, and alternative clinic settings would have been found.

The intervention lasted between 10-12 sessions and the main elements of therapy included self-monitoring through recording daily activity and mood, goal setting and activity scheduling. There were three key phases to the therapy. The first phase (sessions 1-5) involved introducing the client and support person to the intervention and carrying out exercises to assess the client's current level of activity, the barriers to engagement in activity and their level of withdrawal. These exercises consisted of a pictorial task, where the client and supporter selected pictures of activities they

Behavioural Activation for depressive symptoms

currently engage in, activities they have stopped and activities they would like to do. A second task involved looking at the client's broader life goals. The focus was on three life domains: i) domestic activity, ii) meaningful daytime activity, and ii) social activities. In this first phase, the client and support person also began trying out scheduled activities between sessions. This first phase culminated in the client and support person being given a booklet outlining the factors contributing to their withdrawal and suggesting a shared plan for increasing the person's engagement in meaningful activity.

The second phase (sessions 6-10) involved practicing scheduled activities and tackling other barriers to change that had emerged when trying out scheduled activities or that were highlighted by the clients or their supports in therapy sessions. These barriers included emotional or inter-personal difficulties such as anxiety or anger related difficulties preventing people from taking part in activities, and organisational factors such as the adequacy of support for clients. The therapist discussed the barriers with her supervisor and clear guidance and materials were provided for this time limited work. Approaches taken with clients in the study included brief anger and anxiety management, and exercises to increase confidence.

The third and final phase of the intervention (sessions 11-12) was used to review the client and support person's successes before going onto present them with an individualised booklet describing their achievements, highlighting factors that contributed to their success and offering guidance for maintaining and continuing their progress. Suggested strategies for clients and supporters taking part in the feasibility study included building more structure into clients' lives by developing

Behavioural Activation for depressive symptoms

routine daily activities, outlining ways to maintain motivation (with suggestions for both the clients and their supporters), and ways of dealing with anxiety provoking situations.

The aim was also to foster a collaborative approach and to allow the client to play as active a role as possible in sessions alongside their support person. When working with individuals who had more significant impairments some of the content of the sessions could also be adapted to watch the client and support person engaging in activity together, rather than talking about what they had done or intended to do.

The optimal number of sessions was twelve but there was flexibility to end therapy after ten sessions if the therapist, client and supporter felt that targets for increasing activity had been achieved and that there were no remaining barriers that would impede progress.

Procedure

Participants were recruited from specialist Community Teams for people with an intellectual disability in the West of Scotland. The recruitment strategy targeted Psychologists, Psychiatrists and Community Nurses, who were all dealing with their clients' mental health problems. Team members were asked to identify clients they worked with who had depressive symptoms and they believed could benefit from behavioural activation. The Community Team members then handed out information packs to potential participants, who returned a slip by post to the research team, if they wished to obtain further information or to consent to be involved in the study. When a participant did not have the capacity to consent to participate in the study, in

Behavioural Activation for depressive symptoms

keeping with the Adults with Incapacity Act (Scottish Executive, 2000), consent was sought from their relative, or welfare guardian.

Data was collected at the client's home and an independent researcher met separately with the client and their support person to complete the depression and general well-being assessments, and the activity measures were completed jointly.

Ethical approval for the study was obtained from the Scotland A ethics committee.

Analyses

Paired t tests were used to analyse the data obtained for the outcome measures concerning depressive symptoms, activity and general well-being.

Results

Recruitment, Acceptability & Compliance

Twenty three participants were recruited. Twenty one of these participants completed therapy and two participants dropped out. One man moved to another part of the country and a second person decided that she no longer wanted to take part in therapy and withdrew. The socio-demographic details of the 21 individuals who remained in the study are outlined in table 1. It is noteworthy that this included 3 participants with more significant intellectual disabilities. These three individuals and one other person did not have sufficient ability to complete the self-report measures reliably. As table 1

Behavioural Activation for depressive symptoms

shows, the majority of significant others who offered support were paid carers from residential services. Four family members, who were all mothers, also supported participants. Finally, three workers from health and social services, who were providing regular outreach support, attended sessions with clients.

Retention

Only a further two of the twenty one participants who completed treatment were subsequently lost to 3 month follow-up, demonstrating good overall retention.

Outcome measures

Depressive symptoms

Self-report: The mean scores are shown in table 1 and figure 1 also provides evidence of positive change in participants' depressive symptoms following therapy. Seventeen participants had sufficient ability to complete the Glasgow Depression Scale (Cuthill et al, 2003) and missing baseline data meant that one further individual was lost to the pre- to post intervention analysis. There were significant reductions in reports of depressive symptoms and strong effect sizes pre to post intervention $\{t(15) = 4.85, p < .001; r = .78\}$ and pre to 3 months follow-up after completing the intervention $\{t(13) = 6.22, p < .001; r = .86\}$. There continued to be a downward trend between the post intervention and follow-up scores on the GDS $\{t(14) = 2.65, p = .019\}$.

Figure 2 shows that 8 of the 16 participants scored above the clinically significant score of 13 on the Glasgow Depression Scale at baseline. Post intervention, 5 of these participants' scores fell below the clinically significant cut-off. Two of the remaining

Behavioural Activation for depressive symptoms

participants' depressive symptoms had also reduced and there was a marginal increase for the final individual. The same pattern was apparent for the pre-intervention to three month follow-up scores. Follow-up scores were obtained for seven participants who began with clinically significant scores; six of them had reduced to below the clinically significant cut off and the remaining participant's symptom score was also much reduced.

The same downward pattern was observed for those whose scores began below the clinical threshold, with a mean reduction of 5.25 points, from baseline to post intervention and only one participant's score remaining at the same level. There was a further drop in four of the participants' scores from post intervention to three month follow-up, with only one participant's depressive symptoms increasing to their baseline level.

Carer report: The Intellectual Disabilities Depression Scale (Evans et al, 1999), also provided evidence of positive change pre and post intervention $\{t(20) = 4.34, p < .001; r = .7\}$ and from pre-intervention to 3 months follow-up $\{t(17) = 4.22, p = .001; r = .72\}$. There was a continuing downward trend between post intervention and follow-up carer reported depression scores but the reduction was not significant $\{t(16) = 1.6, p = 0.13\}$. Figure 2 shows the downward trend in the pattern of scores on the IDDS across the three data collection points.

Activity

The reported level of community activity on the ICI (Raynes et al, 1989a) remained relatively static between pre and post intervention $\{t(20) = -.123, p = .9\}$ However, there

Behavioural Activation for depressive symptoms

was some evidence of an increase in community based activity between pre intervention and three month follow-up on the ICI { $t(17) = 2.45, p = .025$ }. There was no evidence of a change in the pattern of domestic activity pre to post intervention { $t(20) = -.376, p = .711$ } or pre intervention to follow-up { $t(17) = 1.09, p = .287$ } on the Index of Participation in Daily Life (Raynes et al, 1989).

General well-being

Significant positive changes were also found on the HoNOS-LD (Roy et al, 2002) at both pre and post measures { $t(20) = 4.7, p < .001$ } and at three month follow-up { $t(13) = 4.6, p < .001$ }.

Discussion

Recruiting 23 participants with limited resource from one geographical area, over a fourteen month period, suggests that it is possible to identify individuals with symptoms of depression for a larger scale study. Good compliance and low drop out also points to the acceptability of the adapted version of behavioural activation used in the study. Retaining all participants who completed therapy, bar two, to the follow-up stage of the study, also points to the feasibility of examining the maintenance of effects in a larger scale evaluation. The main outcome measures of self and carer report of depression also appeared to be sensitive to change, showing positive effects post treatment and at three month follow-up. Improvements in depressive symptoms were consistently reported by the clients themselves and their support persons. Of particular importance is the fact that the participants with more severe intellectual disabilities, ordinarily excluded from psychological therapies of this nature, also

Behavioural Activation for depressive symptoms

appeared to benefit from the intervention. In addition, positive changes were found using a broader measure of clinical change, the HONOS-LD (Roy et al., 2002).

Limited evidence was found to suggest there had been an increase in the participants' level of activity. This seemed, in part, due to problems with the measures of community and domestic activity that were used (Raynes, Sumpton, and Pettipher, 1989a; Raynes, Sumpton, and Pettipher, 1989b). The scope of activities did not cover the range of pastimes reported by the participants, including going to bingo.

Moreover, the measures were not designed to detect small changes in the frequency of activities, even though there were instances where such changes appeared to be of considerable salience to the participants themselves. Another plausible explanation is that the adapted behavioural activation therapy simply failed to stimulate any detectable increase in the participants' level of activity. To find out whether behavioural activation does, in fact, increase people's level of activity then careful selection or adaptation of measures would be required, to ensure that the items included were culturally relevant to the study population and the measurement was sensitive to small changes over time.

There are clearly limitations to examining the feasibility and acceptability of a psychological intervention through the use of quantitative measures alone. Although not reported in this paper, four participants and their carers were interviewed about their perceptions of taking part in the behavioural activation treatment and the acceptability of the approach (Jahoda et al, 2013). The participants expressed favourable views of the treatment and valued the therapeutic relationship. The carers found the treatment motivating and thought that it helped to achieve a shared

Behavioural Activation for depressive symptoms

understanding of the participants' difficulties, and a common approach to working with the participants. Clearly, a fuller qualitative exploration of the participants' experiences of treatment would provide a better understanding of the process and acceptability of treatment that would compliment the quantitative data reported in this paper.

The study has direct clinical utility and highlights the importance of building an evidence base about the use of a broader range of psychological interventions for people with intellectual disabilities (Hastings, 2013). However, it would be misguided to use these findings as part of the continuing debate in the field of intellectual disabilities about the relative strength of cognitive and behavioural interventions (Sturme, 2006). In general adult mental health services there appears to be a greater openness to using a range of approaches that are found to be effective, offering a degree of choice and allowing both professionals and clients to identify an approach that addresses their particular difficulties but also fits with their world view, individual characteristics and circumstances (Bower and Gilbody, 2005).

An important consideration is whether Behavioural Activation would be accessible to people with intellectual disabilities and depression. The therapy in this study was delivered by a research psychologist with experience of delivering psychological therapies, under the supervision of a clinical psychologist. The fact that she was not a trained therapist suggests it may be possible for health professionals with experience of working with individuals who have an intellectual disability, like community nurses and Occupational Therapists, to be trained and supervised to deliver Behavioural Activation. If a wider workforce could be trained to deliver Behaviour

Behavioural Activation for depressive symptoms

Activation, with fidelity to the adapted manual, this would help to ensure that the therapy is more easily accessible.

It is noteworthy that only eight out of the sixteen participants who completed the self-report version of the Glasgow Depression Scale (Cuthill, Espie and Cooper, 2003), reached the clinical threshold. One implication of this pattern of recruitment is that clearer inclusion criteria are needed to identify individuals with clinically significant levels of depression. However, all the participants recruited were in receipt of specialist support due to mental health problems. Hence, the sample of participants might also reflect the difficulty with recruiting people who have a straightforward diagnosis of depression. Instead, their low mood may have been linked to other problems like anger and anxiety related difficulties. An alternative future strategy might be to offer behavioural activation to individuals with low mood or symptoms of depression, where it occurs alongside other emotional or inter-personal difficulties. For a future larger scale evaluation, it would certainly seem important to assess a broader range of emotional difficulties, as possible secondary outcomes.

The adapted behavioural activation therapy had a number of components, including self-monitoring and scheduling activities. Kanter et al (2010) have highlighted that it would be helpful for future research to try and assess the contribution of the different elements of the approach. However, it may also be a combination of factors that prove effective. In the present study, when the therapist was working with the clients to overcome barriers to change, she was also prepared to address the clients' emotional concerns. Where clients had sufficient expressive and receptive verbal ability, this included dealing with thoughts and feelings relating to depression, anger and anxiety.

Behavioural Activation for depressive symptoms

Even if we had wished to cut out all cognitive components, and this was not our aim, it would be mistaken to assume that in an inter-personal therapeutic encounter it is possible to seal off dialogue about people's thoughts and feelings relating to their distress. Although the adapted therapeutic approach was based on Lejuez et al (2001), being open to talking with clients about their thoughts and feelings is consistent with the views set out in Lejuez et al's (2011) updated manual of Brief Behavioural Activation. Interestingly, Lejuez et al's updated manual also stressed the value of involving significant others in order to achieve meaningful change in the clients' lives.

Carrying out behavioural activation with clients with an intellectual disability and a support person in their lives was a key adaptation of the approach. This posed challenges, and there were instances where the client and support person did not enjoy good relationships. There may also have been occasions when the clients and support persons were reluctant to express their true feelings in each others' presence. Yet gaining insight into these relationships could, in itself, provide important information about factors impeding change or ways forward. There were several instances when negotiating a change of support person proved to be an important element of the intervention. In any future investigation of behavioural activation it would be helpful to examine the process of change and to establish whether an improvement in the relationship between the client and their support person is associated with a reduction in depressive symptoms.

Involvement of support persons also helped to make the intervention accessible to people with more severe and profound impairments. Although the clients with more

Behavioural Activation for depressive symptoms

severe intellectual disabilities had limited ability to participate in the formal sessions, it was possible to use the manual when working alongside the support person and to compliment this with observations of the support person and client engaging in activity. There remains an absence of psychological interventions for people with more severe and profound intellectual disabilities and emotional problems.

Consequently, it would be important to build on this tentative evidence and to investigate further the value of this approach for people with more severe intellectual disabilities and to establish in a more rigorous fashion if it is possible for therapists to carry out the intervention in a way that maintains fidelity to the manual.

As previously stated, without any control or comparison group it is not possible to say with any certainty whether the positive findings obtained in this study are due to the use of behavioural activation. The passage of time, therapeutic support and simply offering the client and their support person greater insight into their difficulties are just three possible factors that may have contributed to change. Nevertheless, it remains vital to develop an evidence base of psychological interventions that are accessible to people with intellectual disabilities and mental health problems. The experience from this pilot work is that it is not always possible or wise to simply take an existing intervention from the general population and apply it with minimal adaptation to people with intellectual disabilities. Careful thought is required to ensure that adapted interventions are both accessible and relevant to individuals' lives. Given the major inequalities people with intellectual disabilities face in gaining access to health services there may be an understandable temptation to move quickly towards randomised controlled trials. However, it could be argued that greater efforts are required to pilot and assess the feasibility of therapeutic interventions to ensure

Behavioural Activation for depressive symptoms

that definitive trials are based on solid foundations, offering the best chance of successful funding and positive outcomes.

Behavioural Activation for depressive symptoms

References

Beck A.T., Steer R.A. & Brown G.K. (1996) BDI-II, Beck depression inventory: manual. 2d ed. Boston: Harcourt Brace

Bower P. & Gilbody S. (2005) Stepped care in psychological therapies: access, effectiveness and efficiency: Narrative literature review. *British Journal of Psychiatry* 186, 11-17

Collishaw S. Maughan B. & Pickles A. (2004) Affective problems in adults with mild learning disability: the roles of social disadvantage and ill health. *British Journal of Psychiatry*, 185:350-351

Cooper S-A., Smiley E., Morrison J., Williamson A. & Allan L. (2007) An epidemiological investigation of affective disorders with a population-based cohort of 1,023 adults with intellectual disabilities. *Psychological Medicine*, 37:873-882.

Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew, M (2008) Developing and evaluating complex interventions: the new Medical Research Council guidance. *British Medical Journal*, 337:979-983

Cuijpers P., van Straten A., Andersson G. & van Oppen, P. (2008) Psychotherapy for depression in adults: A meta-analysis of comparative outcome studies. *Journal of Consulting and Clinical Psychology* 76, 909-922.

Behavioural Activation for depressive symptoms

Cuthill F.M., Espie C.A. & Cooper SA. (2003) Development and psychometric properties of the Glasgow Depression Scale for people with a Learning Disability. Individual and carer supplement versions. *British Journal of Psychiatry* 182:347-53.

Dagnan D. Chadwick D.P.J. (2000) Toward an Assessment of Suitability of People with Mental Retardation for Cognitive Therapy *Cognitive Therapy and Research*, 24:627-36.

Dimidjian S., Hollon S.D., Dobson K.S., Schmalting K.B., Kohlenberg R.J., Addis M.E., Gallop R., McGlinchey J.B., Markley D.K., Gollan J.K., Atkins D.C., Dunner D.L. & Jacobson N.S. (2006) Randomized trial of behavioral activation, cognitive therapy, and antidepressant medication in the acute treatment of adults with major depression. *Journal of Consulting and Clinical Psychology* 74:658-70.

Ekers D., Richards D. & Gilbody S. (2008) A meta-analysis of randomized trials of behavioural treatment of depression. *Psychological Medicine* 1-13

Evans K.M., Cotton M.M., Einfeld S.L. & Florio T. (1999) Assessment of depression in adults with severe or profound intellectual disability *Journal of Intellectual and Developmental Disability*, 24:147-160.

Hastings R. (2013) Running to catch up: a rapid generation of evidence for interventions in learning disability services. *British Journal of Psychiatry* 203: 245-246

Behavioural Activation for depressive symptoms

Jahoda A., Dagnan D., Stenfert Kroese B., Pert C. & Trower P. (2009) Cognitive behavioural therapy: From face to face interaction to a broader contextual understanding of change. *Journal of Intellectual Disability Research* 53:758-771

Jahoda, A., Dagnan, D., Jarvie, P., and Kerr, W. (2006) Depression, social context and cognitive behavioural therapy for people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19, 81-89.

Jahoda, A., Melville, C., Cooper, S-A., Pert, C., Lynn, H., Williams, C. and Davidson, C. (2013) *Final Report: A pilot study of behavioural activation for depressive symptoms in adults with learning disabilities (PN08CP457)*. Research and Development: NHS Greater Glasgow and Clyde.

Jacobson N. S., Martell C. R. & Dinidjian, S. (2006) Behavioral Activation Treatment for Depression: Returning to Contextual Roots. *Clinical Psychology: Science and Practice* 8, 255-270

Kanter J. W., Manos R. C., Bowe W. M., Baruch D. E., Busch A. M. & Rusch L. R. (2010). What is behavioral activation? A review of the empirical literature. *Clinical Psychology Review* 30, 608–620.

Lejuez C.W., Hopko D.R., Hopko S.D.A (2001) Brief behavioral activation treatment for depression. Treatment manual. *Behaviour Modification* 25:255-86.

Behavioural Activation for depressive symptoms

Lejuez C.W., Hopko D.R., Acierno, R., Daughters, S. B., and Pagoto, S. L. (2011)

Ten Year Revision of the Brief Behavioral Activation Treatment for Depression:

Revised Treatment Manual. *Behaviour Modification* 35:111-161.

Lunsky Y. & Benson B. A. (2001) Association between perceived social support and strain, and positive and negative outcome for adults with mild intellectual disability.

Journal of Intellectual Disability Research 45, 106–114.

McCabe M.P., McGillivray J.A. & Newton D.C. (2006). Effectiveness of treatment programmes for depression among adults with mild/moderate intellectual disability.

Journal of Intellectual Disability Research 50, 239-47.

McGillivray J.A., McCabe M.P. & Kershaw M.M. (2008). Depression in people with intellectual disability: an evaluation of a staff-administered treatment program.

Research in Developmental Disabilities 29, 524-36.

S. Moss, E. Emerson, C. Kiernan, S. Turner, C. Hatton, A. Alborz (2000)

Psychiatric symptoms in adults with learning disability and challenging

behaviour. *British Journal of Psychiatry*, 177: 452–456

Raynes N.V., Sumpton R.C & Pettipher C. (1989a) *The Index of Community*

Involvement, University Department of Social Policy and Social Work. Manchester,

UK.

Behavioural Activation for depressive symptoms

Raynes N.V., Sumpton R.C. & Pettipher C. (1989b) *The Index of Participation in Domestic Life*, University Department of Social Policy and Social Work. Manchester, UK.

Roy A., Matthews H., Clifford P., Fowler V. & Martin D. M. (2002) Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) *British Journal of Psychiatry* 180, 61–6.

Sams K., Collins S. & Reynolds S. (2006) Cognitive therapy abilities in people with learning disabilities. *Journal of Applied Research in Intellectual Disabilities* 19:25-33.

Scottish Executive (2000) *Adults with Incapacity (Scotland) Act*. The Stationery Office, Edinburgh.

Stancliffe R.J., McVilly K.R., Radler G., Mountford L. & Tomaszewski P. (2010) Active support, participation and depression. *Journal of Applied Research in Intellectual Disabilities*, 23:312-321.

Sturmey P. (2006) On Some Recent Claims for the Efficacy of Cognitive Therapy for People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* 19, 109-117.

Behavioural Activation for depressive symptoms

Willner P. (2006) Readiness for cognitive therapy in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 19, 5-16.

Table 1 Socio-demographic details of the participants who completed the intervention

Characteristic	Participants
Number	21
Sex	
Male	12
Female	9
Age Range	21-63
Mean Age	42.2
Std Deviation	13.5
Intellectual Disability	
Mild	16
Moderate	3
Severe	2
Physical Disabilities (wheelchair/limited mobility)	5
Housing	
Individual Tenancy	9
Small group home	3
Cluster	4
accommodation	5
Family Home	
Carer Support	
Paid Carer	14
Family Carer	4
Statutory Services (e.g. nursing assist.)	3

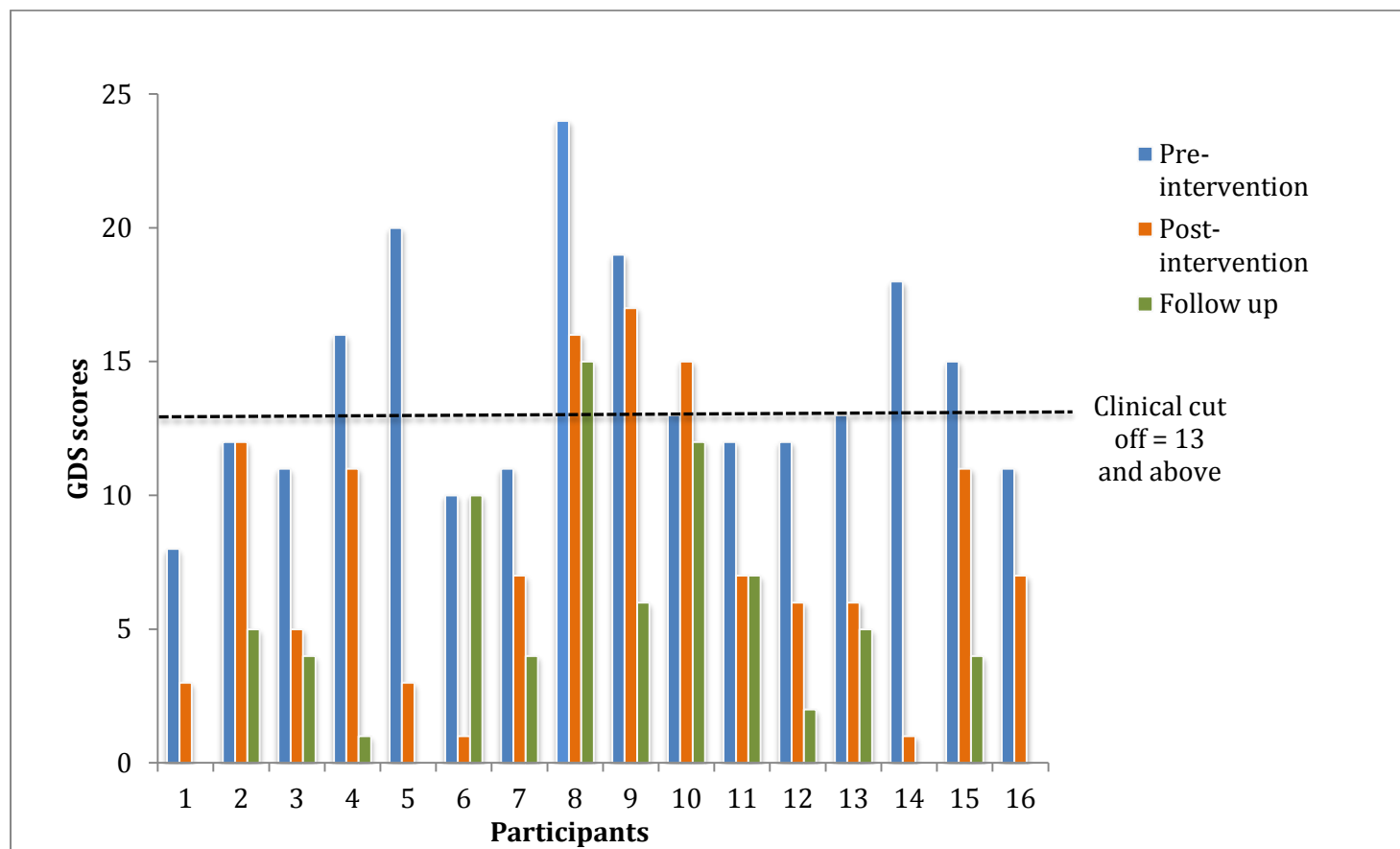
Behavioural Activation for depressive symptoms

Table 2. Group scores for Self and Carer report of depression, activity levels and wellbeing.

Measures	Pre-Intervention	Post-Intervention	Follow-up
GAS-ID Depression self report	N(16) Mean: 14.06 SD: 4.28 Range: 8 -24	N(16) Mean: 7.88 SD: 5.21 Range: 1 - 17	N(14) Mean: 5.36 SD: 4.43 Range: 0 -15
IDDS Depression carer report	N(21) Mean: 57.2 SD: 31.54	N(18) Mean: 29.9 SD: 13.15	N(18) Mean: 23.72 SD:13.78
IPDL No. activities daily life	N(21) Mean:11.62 SD: 7.35	N(21) Mean: 12.05 SD: 6.77	N(18) Mean: 10.06 SD: 7.92
ICI No. community activities	N(21) Mean: 7.3 SD: 2.3	N((21) Mean: 7.33 SD: 2.15	N(18) Mean: 5.61 SD: 2.28
HONOS – LD Wellbeing	N(21) Mean: 13.95 SD: 5.82 Range: 5 - 25	N(21) Mean: 7.9 SD: 5.42 Range: 1 - 19	N(18) Mean: 7.44 SD: 5.68 Range: 0-21

Behavioural Activation for depressive symptoms

Figure 1: Participants' GDS scores: Pre-intervention, post-intervention and at follow up



Behavioural Activation for depressive symptoms

Figure 2: Participants' IDDS Scores at Pre-intervention, post-intervention and at follow up

