



Committing to Collaboration; Enabling Recovery



January 2016

Project Title: Committing to Collaboration, Enabling Recovery

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1. Summary

Aim

We aimed to equip individuals with the ability to recognise when they are well and what can keep them well, to recognise when they are unwell and what can make them unwell and what supports can be utilised which can help them move from being unwell to well again. The resulting education and sharing of experiences were used to create a feeling better keeping well plan that they took away with them at the end of the project and were encouraged to share with their carers, family or others who may support them.

We also wanted these sessions to be a starting point towards embedding the recovery language and principles into the care and treatment of adults with learning disabilities who also have a co-morbid mental health diagnosis.

Method

Individuals with learning disabilities were invited to attend a series of 10 group sessions along with a paid carer, unpaid carer or family member. Information was provided in a variety of formats to help participants think about what keeps each of them well and in doing so help them identify what they can do to maintain wellbeing and aid their recovery following any period of mental ill health.

Sessions were based around each participant, including facilitators creating their own feeling better keeping well plan, by finding from the materials provided things that helped them feel well and stay well or made them feel unwell; these were then stuck onto the wellness plan template provided for each person.

We actively involved Local authority staff, third sector staff and family carers who both helped to facilitate group activities and participated in developing their own plans. All participants completed pre and post course surveys,

Results

We initially had 84% (n= 10/12) return on pre course survey to establish baseline. Drop out during course 25% (n=3) and return of post evaluation material 42% (n = 5). All participants enjoyed the course with Healthy eating and activity, relaxation and keeping busy being rated as the top three most useful sessions.

Conclusion

Recruitment and retention of participants was difficult despite our efforts to advertise the course in an accessible format, this may be due to self-determination and motivation which can be significantly impaired in people with learning disabilities. Travel constraints, limited access to staff support and commitment to regular sessions during the winter months were also noteworthy factors.

2. Background

As newly appointed Advanced Nurse Practitioners in mental health and learning disability services we were keen to explore the wellness and recovery agenda in mental health care provided to adults with Learning disabilities in Aberdeen City and Aberdeenshire . As we were aware of the lack of reference made to this agenda in Learning disability services it was felt that a pilot project to offer Recovery/ wellness sessions to this population could be the first steps toward developing practice based resources that promote wellbeing, manage relapse and encourage health seeking behaviour. We hoped to increase individuals understanding and insight in relation to their mental health conditions.

The concept of recovery as an underpinning philosophy for mental health services has been seen as a driver towards a more person centred approach by placing the emphasis upon an individual's life story, personal values and supports in order to strengthen resilience (Roberts and Hollins, 2007). Recovery based practice is clearly evident in main stream mental health services however there is limited practices focusing on recovery and wellbeing in mental health services for people with learning disabilities. A clinical diagnosis of Learning Disability (LD) is reached following a standardised intelligence test and social adaption assessment (WHO ICD-10 2007). The results of this testing can be categorised into; Mild (LD) where an individual has a Intellectual Quotient (IQ) that is between 50

and 69, moderate between 35 and 49, severe being between 20 -34 and profound if IQ is below 20. The recognition and diagnosis of mental disorders in people with learning disabilities is particularly difficult, partly because of communication limitations, which often make it difficult for the individual to describe symptoms, and partly as a result of diagnostic overshadowing (ascribing the symptoms of mental illness to the person's life-long learning disability) (Levitan & Reiss 1983).

People with Learning Disabilities have a higher prevalence of mental health difficulties than that of the general population with rates of 30-50%. This predisposition to mental ill-health is apparent across the lifespan, including in children, young people and adults (Einfeld et al., 2006), (Emerson & Hatton 2007). The vulnerability to mental disorder is complex, and arises from interplay between the learning disability and other medical, social and psychological factors. The presence of a learning disability usually affects a person's coping skills and autonomy, creating greater susceptibility to stress, and thereby increasing psychological vulnerability (Janssen, Schuengel & Stolk 2002). There is growing evidence over several years identifying that people with Learning Disability also have greater and differing physical health needs than the general population (Hollins et al., 1998) ; this can then have a direct impact upon an individuals' general wellbeing and mental health. Further risk arises from the reduced opportunities to engage in a range of life choices, and restricted social networks that people with a learning disability often experience. Given the increased prevalence of both physical and mental health difficulties in the learning disabled population (Deb et al., 2001) we felt it to be important to consider if a recovery / wellness approach would be of benefit to adults with mental health conditions and a co- existing learning disability.

Clinical recovery calls for both symptom relief and "the restoration of cognitive, social and occupational functioning" (Davidson et al., 2005) therefore we needed to take into consideration what recovery would look like for individuals who had Learning Disabilities whose functioning in these areas is already compromised. Research by Cheffey et al., (2010) and Daley and Newton (2010) identified the need for differing approaches with regards to the recovery model in older peoples' Mental Health services including the recognition of the balance between empowerment, dependence and cognitive decline. The mainstream recovery model allows for the adjustment of expectations, this principle was shown to be central to the application of the model in services for older adults and implies that the definition of recovery can be defined differently across client groups.

Studies on recovery have noted that the process of self-monitoring of symptoms, recognising early warning signs of illness, and developing a plan to deal with crisis situations were self-help strategies essential to the process of recovery and self-management.

(Copland, 2001; Fisher,1998; Henderson et al., 2004 and Sullivan, 1994)

3. Aims & Objectives

Due to the increased likelihood of poor physical and psychological wellbeing in the learning disability population our aim was to give individuals the opportunity to share their experiences, listen to others who may struggle with similar issues and develop an understanding of how wellness can be achieved and maintained in spite of having a mental health condition. We also wanted participants to recognise what works best for them as an individual and with this in mind we felt the best approach was to enable course participants to develop their own unique feeling better keeping well plans. The session will provide a general overview of Physical and Psychological aspects of wellbeing and we hope to then link this course with work currently being undertaken locally by community learning disability nurses relating to person centred wellness action plans.

We aimed to:

1. Provide a 10 week community based programme consisting of interactive group sessions to adults with learning disabilities and mental health conditions in order to increase and enable greater understanding of how they can work individually and in collaboration with professionals to manage and maintain their own wellbeing.
2. We aimed to equip individuals with the ability to recognise when they are well and what can keep them well, to recognise when they are unwell and what can make them unwell and what supports can be utilised to enable them move from being unwell to well again.
3. Our objective was that each participant would develop their own feeling better keeping well plan in the form of a poster to take away at the end of the course.
4. We aimed to actively involve paid, unpaid and family carers who will be encouraged to attend to both support individuals and to consider their own wellbeing needs. We were also aware of research identifying the importance of involving carers in order to achieve a significant effect upon health outcomes, as carers may be involved in the decisions around lifestyle choices (McGuire et al., 2007).
5. The 10 sessions' would be held within local community resources. Three sessions would provide education with regards to healthy eating, exercise and meaningful activity / active support and were to be provided by professionals from local community Learning Disability teams and third sector agencies.

6. The remaining sessions would attend to feeling sad, managing anxiety, stressors, stress management and relaxation.

7. In each group session both the client and the carers would work on their own feeling better keeping well poster with support of course facilitators, identifying what keeps them well, what can contribute to making them unwell and the factors that can aid recovery. As the sessions progress and information is provided each participant will be encouraged to revisit their posters to review and add to their plans.

8. We recognise that approaches to the treatment of mental health issues in the Learning Disabled population may need to be adapted if the goal is to promote well-being rather than solely treating illness. In order to do this we aim to promote a wellness / recovery model to professionals within the Community learning disability and Local authority teams, third sector staff and family members via both participation in the groups and assistance with the facilitation of sessions.

9. To aim for the publication of resources for use with adults with Learning disabilities to enable the development of staying well plans and client held support plans focusing on wellness and recovery. We also aim to work with Community Learning Disability Nurses who are currently developing a local Wellness plan which has a greater focus upon the specific presentation of an individual's mental health condition and relapse profile in the hope that this format can be used alongside our more overarching feeling better keeping well plans.

4. Method & approaches

This project involved individuals with learning disabilities attending a series of group sessions along with a paid carer, unpaid carer or family member at which they would receive information about the importance of understanding what keeps each of them well and in doing so help them identify what they can do to maintain wellbeing and aid their recovery following any period of mental ill health. It is fair to say that similarities between recovery and practices already being implemented in services for people with intellectual disabilities such as person centred care are evident in practice however these practices are not explicitly described or labelled as being recovery orientated. With these sessions we want to make that clear link in order to embed the recovery language and principles into the care and treatment of adults with learning disabilities who also have a co-morbid mental health diagnosis.

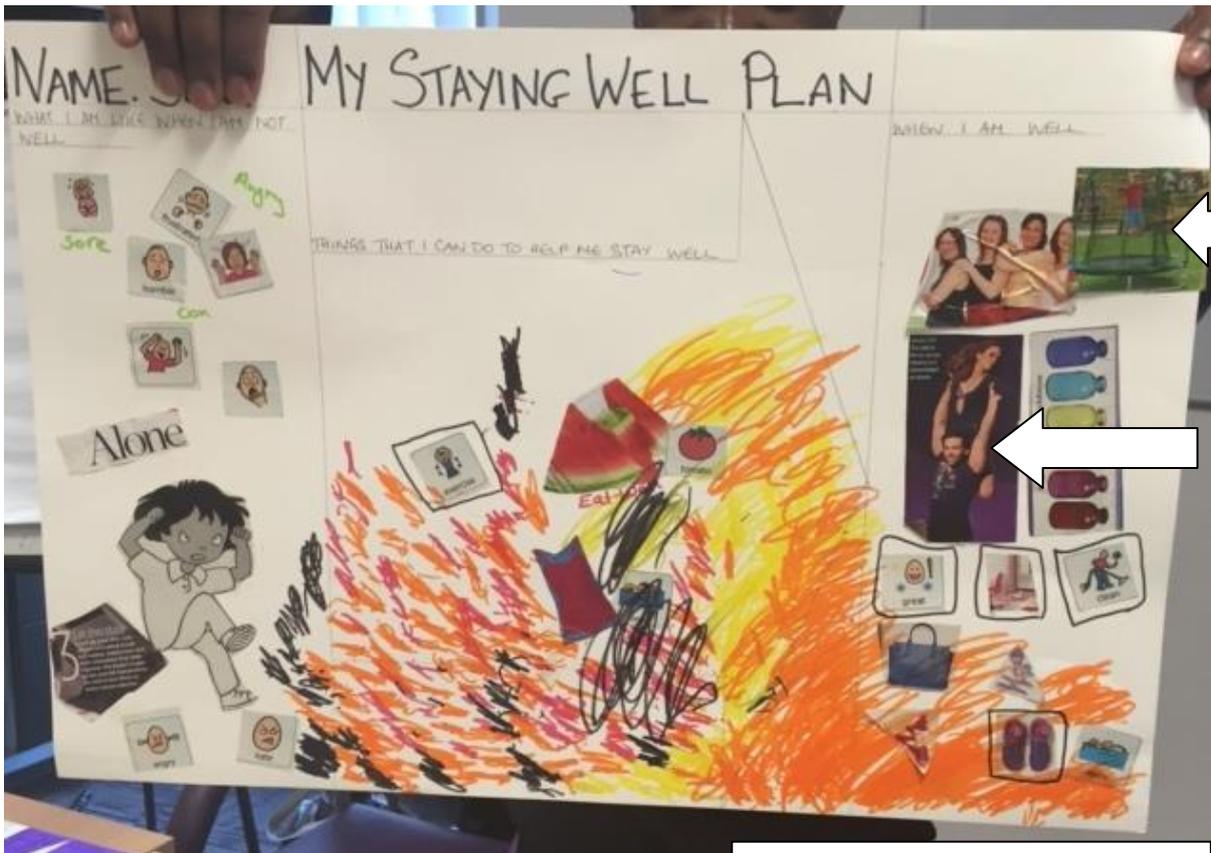
A group format was selected as it was felt that this approach allowed individuals to share their experiences of mental ill health and in doing so normalising their difficulties. Research by Read &

Papakosta-Harvey, 2004; highlighted positive gains for people with learning disabilities linked to being part of a group and the feelings of being able to talk and feel listened to with the group offering a sense of belonging and support.

As we would not know the level of cognitive ability or communication skills of participants prior to the start of the course we would not be able to judge their level of engagement with course materials. Information in group sessions needed to be delivered in an accessible way (Higgins & O'Toole, 2008) to ensure participants are able to understand the material. With this in mind and in order to make communication as inclusive as possible we decided to use a format that would contain pictures and symbols and was mindful of verbally presented information, we took into consideration the pace of sessions, presenting in short sentences and stressing key words, avoidance of Jargon and allowing time for individuals to process information. As retaining and recalling information is also difficult for many individuals with learning disabilities we summarised key themes at the end of sessions and recapped previous sessions at the start of the next class. Sessions were based around each individual, including support staff, family members and facilitators creating their own feeling better keeping well plans by finding pictures or symbols from magazines and printed sheets provided, drawing or writing about things that helped them stay well or made them feel unwell; these were then stuck onto the wellness plan template provided for each person. This activity was interspersed with information sessions to help each person think and talk about exercise, healthy eating, meaningful activity, feelings, thoughts and behaviour.



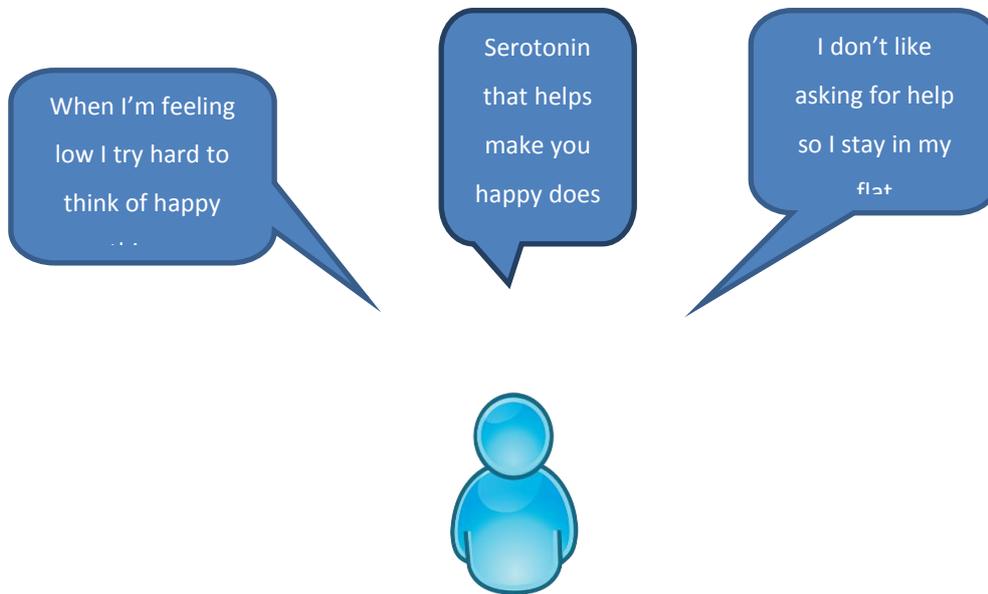
This is one of our course members using an exercise bike, getting her heart rate up and being slightly out of breath as advised by Gordon our Physiotherapist at his session on wellbeing and physical activity.



She then chose the Physical activity that made her feel good as going on the trampoline and dancing.

5. Findings

Throughout the sessions participants often made comments and remarks that amazed us and showed attainment and insight far beyond our own expectations as facilitators.



Participants were requested to complete pre and post course surveys

Catalyst for change pre course evaluation

How much do you know about how your physical health affects your mental health?

NOTHING A LITTLE A LOT

How much do you know about keeping active and mental health?

NOTHING A LITTLE A LOT

How much do you know about Stress?

NOTHING A LITTLE A LOT

Do you know when you are getting stressed?

NOTHING A LITTLE A LOT

Can you do something to help your stress?

Yes No

Do you have a wellness plan?

Yes No

Do you know what to do when your Mental Health is not good?

Yes No

After the course what have you learned?

How much do you know about Stress?





NOTHING A LITTLE A LOT

Do you know when you are getting stressed?





Nothing A LITTLE A LOT

Can you do something to help your stress?




Yes No

Do you have a wellness plan?




Yes No

Do you know what to do when your Mental Health is not good?




Yes No

Catalyst for change ideas for post course evaluation

Which course did you attend?




Aberdeen City Aberdeenshire

Did you enjoy the course?




Yes No

Which session(s) did you find most useful?

1. Introduction to Course- What is being Well and Recovery?
2. Awareness sessions on a variety of topics- Healthy Eating, Exercise, Smoking, Alcohol, Drugs
3. Stress
4. Relaxation
5. Keeping busy
6. Thinking and Feeling
7. Identifying Signs that mean I'm not well- Relapse Signatures
8. Developing Maintenance Plans-
9. Developing Crisis and post crisis plans
10. Outcomes- Evaluation and Feedback.

Which Session was not so helpful?

1. Introduction to Course- What is being Well and Recovery?
2. Awareness sessions on a variety of topics- Healthy Eating, Exercise, Smoking, Alcohol, Drugs
3. Stress
4. Relaxation
5. Keeping busy
6. Thinking and Feeling
7. Identifying Signs that mean I'm not well- Relapse Signatures
8. Developing Maintenance Plans-
9. Developing Crisis and post crisis plans
10. Outcomes- Evaluation and Feedback.

What can we do better?

1. Better Venue
2. Other speakers
3. Talk about other things?

We initially had 84% (n= 10/12) return on pre course survey to establish baseline.

Drop out during course 25% (n=3)

Return of post evaluation material 42% (n = 5)

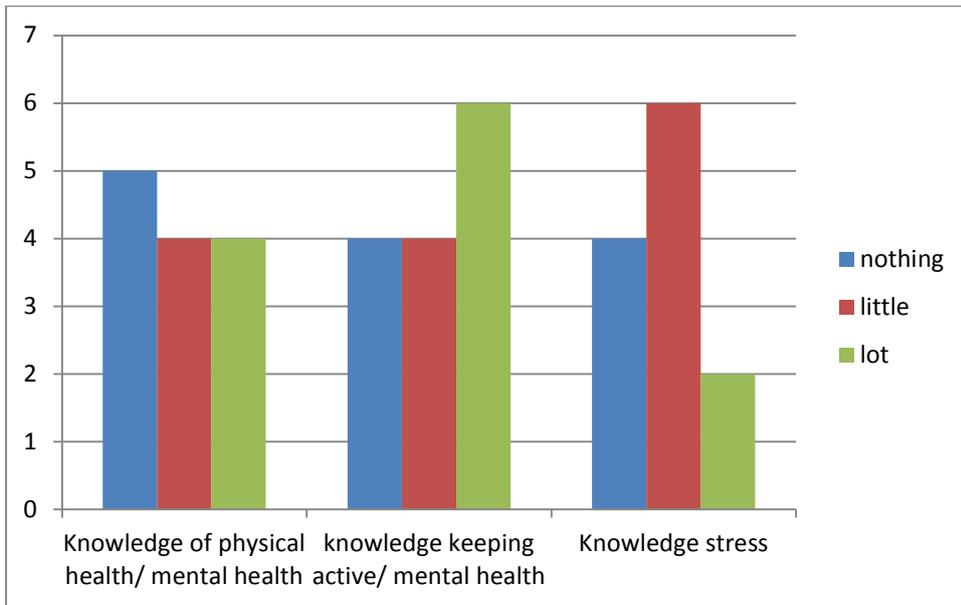


Table 1 Pre course baseline knowledge

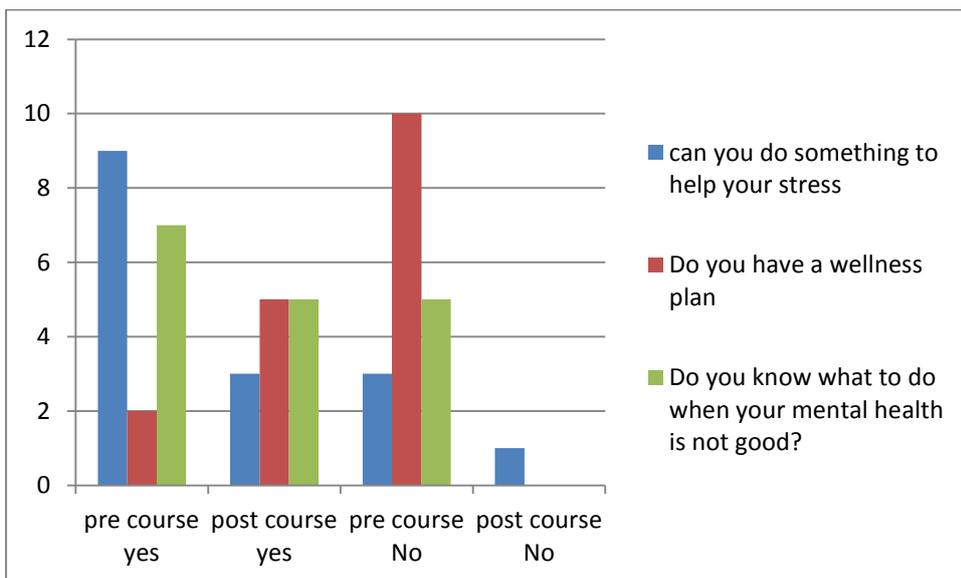


Table 2 Pre and post course evaluation

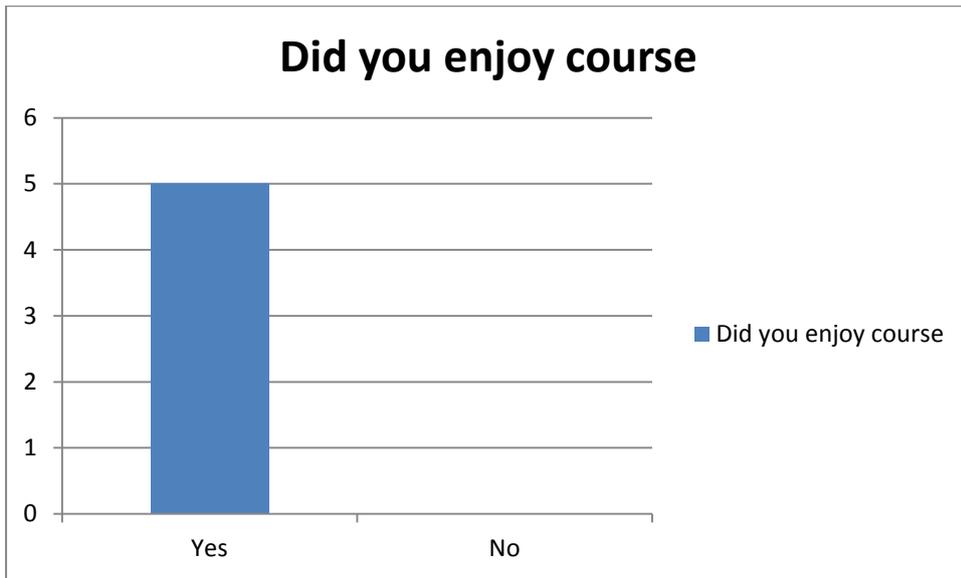


Table 3 Enjoyment

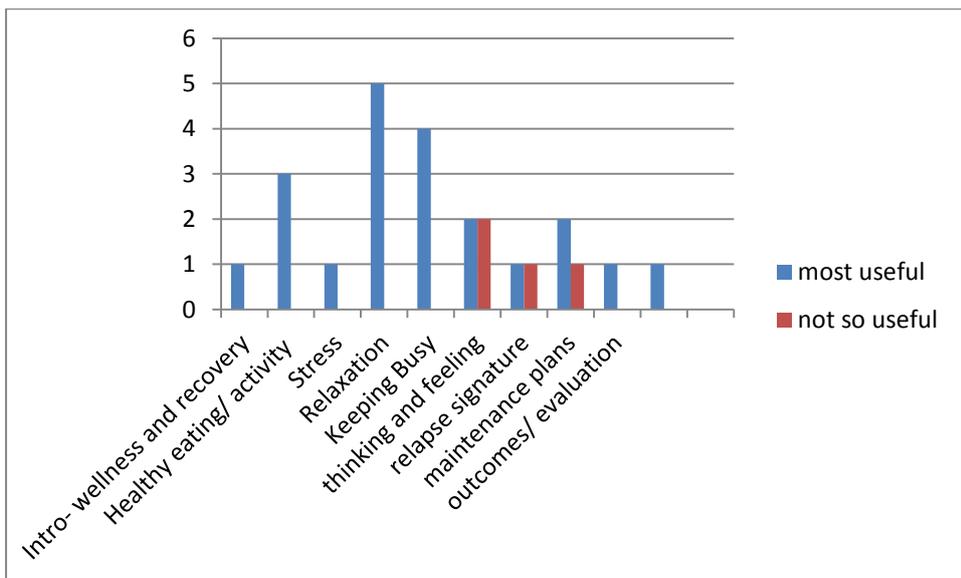


Table 4 most useful and not so useful

General comments also noted on evaluation forms included

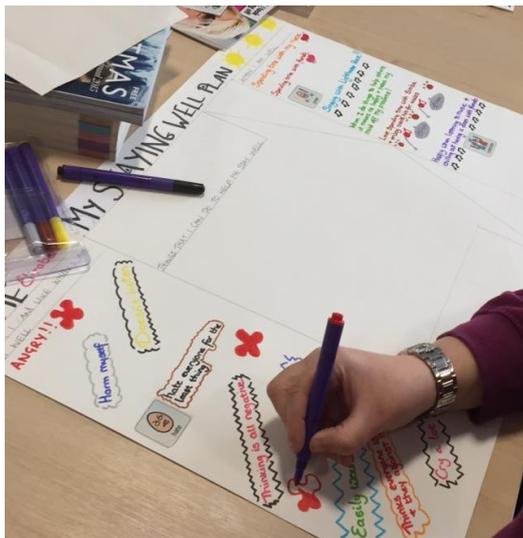
“ I liked them all”

“ I want more groups”

6. Discussion

Only 5- 10 % of people with learning disabilities have any sort of recognised literacy skills and most cannot access standard written formats (Royal college of speech and language therapists 2013), this meant that all formats of communication, information and the development of wellness plans had to be in an accessible format that fitted the individual needs of participants within the group. There was no formal selection process for participants; access to the groups was open for anyone with a learning disability who also had a mental health condition and was interested in staying well and their recovery. Therefore initial planning, sourcing and developing materials also needed to be flexible enough to meet the varying needs of participants who may enrol. It was also important to ensure that the materials used would also promote and enhance individual's insight and their treatment outcomes (2014 Broussard et al). The need to think beyond just presenting information in an accessible, simplified format was essential, some participants needed to absorb information over time with understanding reached in 'the doing' and practising.(Nind,2008). For those who were able to bring a carer or supporter the ability to practise in between groups increased the learning process and enhanced understanding. The blending of psycho education with practised behavioural adaptation was an approach used however the effectiveness of this as a tool to promote understanding and hopefully eventual insight was not something that was evaluated in this pilot.

As facilitators we worked alongside the group in developing our own wellness plan poster and we felt this very useful in terms of normalising the process and modelling behaviour to promote learning.



NHS
Grampian

**Do you have a Learning Disability?
Do you need support around your
Mental Health?**

Psychosis Depression Stress

Bi Polar illness Anxiety



Are you interested in what can keep you well?

NHS Grampian are running a 10 week course for Mental Health Wellbeing, Recovery and Keeping Well. Groups will run from September 2015 to January 2016.

You can choose who supports you to develop your wellness plan this can be family, paid or unpaid carers.

**If you are interested please contact
01224 557153**

Flyer developed to advertise courses

Recruitment was difficult despite our efforts to advertise the course in an accessible format, send out across a number of forums and partners including health, social work and third sector.

Our challenge with recruitment may have been linked to the effect of adherence and self-determination (Corrigan et al 2012), how this affects participation for people with serious mental

illnesses and the evolution to collaboration across all mental health services, not just those for people with learning disability.

In providing services, treatment and support for people with learning disabilities we are constantly striving to promote choice and along with this comes the challenges of ensuring our patients and clients have a perception of the importance and satisfaction of their treatment its processes and outcomes. How far we are in our journey to find adaptations to our practises and approaches to achieve this goal it is unclear. The historical and conventional approach to the treatment of mental health conditions for this client group still remains pharmacological with little evidence that this group are benefitting from the national drive to improve availability of psychosocial interventions. (Fernando 2008, Taylor et al 2013)

As established learning disabilities practitioners we struggle with the dilemma of ensuring choice is self-determined for our client group, whilst minimising the effect our behaviour and communication may have on this. Ethically we hope to ensure that the individual is making a choice in absence of any fear that their choice is unpopular or inappropriate (Harris 2003) and also that our behaviour does not influence individuals to make choices in order to please us.

Our successes included the achievement reached by each participant in completion of the posters and or their plans and the sense of success and accomplishment from each member of the group at their final meetings when these were presented. Everyone who completed the course developed their own staying well poster plan, within one group participants were also supported to develop their own feeling better keeping well plan. These plans had recently been developed by two Community Learning Disability Nurses within the service. This was a recovery focused tool which identified using a traffic light system the clear stages of an individual's progression of illness from onset through to recovery and post crisis reviewing and planning. These were introduced into week 9 and 10 of the programme; at this stage participants had more understanding of their particular health condition, its presentation and were able to identify strategies to help maintain their mental wellbeing. The completion of these was as a homework task and individuals were asked to involve their family and carers to complete. The sense of triumph and success participants had in reporting back and sharing these with group was remarkable. This also served as a check on what individuals had learned throughout sessions and how this learning transferred into individual goals and plans.

Behaviours were also seen to change, participants who arrived with fizzy sweetened drinks came to group with water. Confidence appeared to flourish and those individuals who initially didn't

contribute began communicating sometimes this was only words but with support phrases and meaning was shared (Cambridge and McCarthy 2001).

The project was staff intensive and although feedback on preferred venues was considered and chosen this did not appear to attract as many participants as had hoped.

Practical sessions and the session on relaxation created lots of participation and involvement. There is a notable absence of accessible leaflets and media to support practise of relaxation for this group, previous experiences in the practise of relaxation for participants amounted to listening to music with whales or the sea whilst lying on their bed.

As facilitators our own skills in group facilitation increased as did our skills to modify our approaches to meet the needs of varying levels of cognitive functioning within group settings.

A number of community nurses and allied health care professionals from within community teams supported the groups through education around a number of health promotion topics at specific sessions. For those individuals who had completed feeling better keeping well plans there was a commitment from community nursing to ensure that plans were maintained and revisited at times of crisis for review and modification. As a service this indicated the ongoing change in focus around delivery of support and promotion of wellbeing as well as the treatment of illness.

Through the project a small number of individuals with learning disabilities now have their own Wellness plans and a better understanding of recovery and how to promote wellbeing. The overall impact of the project within the Service included the beginning in a shift from conventional treatment approaches to a more holistic approach where individuals and their recovery are paramount to mental wellbeing.

7. Conclusion

Findings and lessons learned from this project identify a number of implications, potential future developments and areas of study within the field of learning disability and mental wellbeing.

Further service developments identified included

- Supporting Inpatient services so all in patients with mental illness are discharged with Wellness plans
- Development of further focussed wellness topics/sessions within local day centres and group homes in the hope this increases participation due to easier access.
- Development of accessible literature for people with learning disability and mental illness

- A Wellness information board within service clinic area
- Development of resources to support enhanced awareness of relaxation for people with learning disabilities.
- The development of a pack of useful information and guidance on how to develop your own wellness group for the use of third sector, local authority services and service user led groups.

As we strive to ensure our client group are given equity of access to mental health services and effective treatment that stems from evidenced based practice, there remains the challenges around equipping therapists to ensure adaptations are made to include individuals as partners in their own recovery and wellbeing. Difficulties and barriers to involving people with Learning disability in research to contribute and support development of models of delivery that promote most effective outcomes are needed (Taylor and Lindsay 2013).

8. Dissemination

The process of feeding back to professionals informally took place at various intervals during and following the courses. More formal feedback regarding the underlying ethos for commencing the courses, sharing of findings and lessons learnt will be done in a number of ways which will include:

- Feedback at local Learning Disability Multi-disciplinary and Multi-Agency team meetings.
- An overview for the Learning disability service Newsletter.
- An overview for the third sector provider forums in both Aberdeen and Aberdeenshire
- To feedback to Learning Disability Nurse Consultant and Senior Nurse Group
- To use pilot as example of good practice at next local quality event.
- To develop a selection of accessible information for use by other professionals to promote a wellness approach directly with clients and for use by local authority and third sector staff to begin the discussion around keeping well with clients and staff groups.

We hope to use the information to develop a comprehensive article in relation to the wellness and recovery agenda in learning disabilities and submit this to Learning Disability journals for consideration.

9. Next steps

Sharing of our experiences as identified is the first step in getting our message out to a wider number of professionals and service Users. Clearly the development of more accessible information that can be made available to adults with Learning disability and their supports will help to disseminate information regarding wellness and recovery. Placement of this information in day centres and other community resources will help to raise awareness and hopefully demand for more wellness based groups. To sustain this type of intervention we need to work closely with professionals and organisations in order to help them to set up and run local sessions. As we found sustaining participation an issue we need to ask our client groups how we can make access easier in terms of venues, number of sessions and support to attend. We also plan to approach local day centres in order to work towards a regular session slot to look at keeping well and the use of keeping well plans.

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11. Financial report – a brief summary of how the money was sent on a separate page

Money spent to date has been minimal as we continue to wait for costings in relation to publishing of materials which are being developed since the end of the course and in collaboration with Speech and language therapy and community Learning Disability Nurses. These include;

- Development and publishing of accessible staying well booklet
- Publishing of feeling well staying well pack for use in groups
- Wellness and recovery plan paperwork for routine use by Community Learning Disability Nurses.

Committing to Collaboration, Enabling Recovery	
proposed expenditure	
Travel and Accomodation (conference)	250
refreshments at groups (20 sessions)	100
Stationary and Printing	300
Development of Specific Accessible leaflets including publishing	700
Relaxation	
Wellness	
Keeping Well/ Feeling Better plan publishing	400
Development of Relaxation CD for people with LD	700
Resources for groups and wider awareness	500
	2950