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Evaluation of the Manchester Supporting Health Programme for People with Dementia and their Carers
November 2010

There are currently estimated to be 821,884 people in the UK living with a diagnosis of dementia and 163,000 new cases of dementia occur in England and Wales each year. In 2009 the launch of the National Dementia Strategy, 'Living Well with Dementia' put people living with dementia and their carers at the forefront of health policy. The Strategy aims to provide a framework from within which local agencies can deliver improved services which address health inequalities.

Manchester has developed its own local dementia strategy alongside a Manchester Mental Health Commissioning Strategy designed to meet the needs of over 4000 residents who have dementia, and their carers. This number will see a rise of 6% by 2016. The Manchester Dementia Strategy reports a link between dementia and deprivation and states that Manchester is the third most deprived local authority in England. It reports that if older people in Manchester do indeed have a higher level of poor health then this could further impact on incidence of dementia thus making dementia an even greater cause for concern (Manchester Dementia Strategy, 2009).

This report contains the findings and recommendations from a small-scale independent evaluation of a pilot stage of the Manchester Supporting Health Programme for People with Dementia and their Carers.

1. Introduction to the evaluation

According to the original commission, the main aims for the independent evaluation were to:

1. To establish a process of evaluation by April 2009, providing a final evaluation report by November 2010.
2. To provide an appropriate range of baseline indicators for use in measures of the effectiveness of service provision. The baseline indicators will identify:

access to medical and health improvement services for target populations, including those groups for whom there are barriers to access.
systemic improvements in liaison between agencies providing relevant services, e.g. between primary and secondary care.

3. To report on improvements for individuals who use the service with reference to data from service records.
4. To report on subjective views of service users in respect to their use of the service and improved access to routine provision.
5. To report on the views of individuals/services that are either partners in this provision or representative of service users.
6. Provide recommendations for service improvement and development.

Challenges and limitations to the evaluation process

The original plan of the evaluation was for a 3 stage assessment process including an initial scoping exercise followed by 2 evenly spaced ‘snapshot’ assessments of the Programme. A submission to the Integrated Research Application System (IRAS) for ethical approval delayed the start of the evaluation requiring a condensing of the fieldwork and timescale. Delays in recruitment to the Programme itself also meant that the period of time in which to establish and develop the Programme was condensed. These delays are significant to the overall evaluation given that the opportunities to gauge some of the potential longer term effects and benefits to the Programme were reduced. Given the innovative nature of the work being undertaken by the Programme there are good reasons for further on-going evaluation using longitudinal methods.

2. Methods

In revising the evaluation design we took into account the exploratory nature of the Programme given its pilot status and decided that a traditional approach aimed at measuring progress against pre-set objectives would provide information of only limited use to the development of the programme. We drew instead on realist evaluation methods that involve asking ‘what works, for whom and under what conditions?’ Our aim was to provide evidence of where the project had been successful while examining the mechanisms by which that success was achieved as well as identifying the barriers to success and considering how these might be overcome.

Stage One. Scoping Exercise

In order to understand the need for the service and the current level of service delivery for people with dementia regarding their physical health needs we carried out a scoping exercise.

The scoping consultation involved the following organisations:

General Practice: Bodley Medical Practice
Independent and Voluntary Sector Organisations: Age Concern Manchester, Alzheimer's Society, Woodhouse Park Lifestyle Centre, African and Caribbean Care Group for the Elderly, Salvation Army, Young Onset Dementia Service, Booth Centre, Carers' Groups.
Specialist Clinical Services: Cardio Vascular Specialist Service, a CMHT, Manchester Memory Clinics.
Health Improvement Services: Manchester PARS, Manchester Expert Patients Programme.

Stage Two. Fieldwork for the Evaluation

The evaluation gathered evidence from a variety of sources and with fieldwork continuing through to the end point of our evaluation in November.

We undertook a series of site visits and observations at carers groups and health training events as well as shadowing of the Health Check Nurse (HCN) to observe the health check process. Informal discussions were held with team staff and we attended the regular Advisory Group meetings. One to one semi-structured interviews were held with an assortment of stakeholders and these were supported by a review of the service documentation for the Programme.

Interviews:

People with Dementia = 6
Joint interview with PWD and carer = 6
Carers = 5
Staff from organisations allied to the project = 8
Project team members = 4

3. Findings

Findings from the scoping exercise

The scoping exercise aimed to establish what work was already underway concerning dementia and physical health in the city and we sampled a number of different types of providers from different sectors. Overall, the scoping study found that physical health was rarely highlighted in the policies of dementia service providers and few organisations made use of any formal tools in order to assess physical health. For more general health services, dementia was rarely highlighted in their policies and we found none that had a specific protocol for working with people with dementia.

Other messages from the analysis of the scoping data included:

Many of the carers that took part in our consultation reported that their own health needs were neglected by service providers.

The dementia service providers that we spoke to indicated that little work had taken place to date where physical health was a focus

One area of good practice was identified within the cardiovascular specialist service. This service worked with the patient and focused on the individual needs of the patient, supporting those with dementia or other mental or physical disabilities. All patients were assessed with the following questions:

- What is your perception of your illness?
- What are your health beliefs?

Where a focus on physical health had been developed, it was often on an ad hoc basis and dependent on the professional roles included in the team. For example, an OT who had previous experience in older people's physical health had utilised this experience within one service.

Discussions with General Practice highlighted the limited number of referrals made to general services for people with dementia.

Health Improvement services identified numerous barriers to working with people with dementia under their current working practice. The need for specialist training was recognised.

Within voluntary sector organisations and day centres there was an awareness of health improvement issues and an attempt to support health improvement activities. However this was limited by a lack of resources and expertise.

Another example of good practice on physical health and dementia was identified in Manchester's Young Onset Dementia Service where workers supported service users to design a tailored programme using their Direct Payments and offered small group activities such as swimming and walking trips.

A key finding from the scoping investigation was that the response to physical health issues for PWD tends to be reactive rather than proactive and often depends upon the persistence of carers advocating on behalf of the person they care for.

We concluded from the scoping exercise that awareness and promotion of physical health is not systemic in services supporting people with dementia. Much of the support that does exist is organised under the banner of behaviour and concerns over how it is managed. This is also true of much of the training currently on offer to the dementia care workforce. There are clear opportunities for health promotion work with dementia services alongside a need to promote access for people with dementia to community-based resources and facilities that offer health improvement opportunities. There is also potential for the Programme to gather and disseminate existing examples of good practice.

Project Structure and Partnership – an overview

Staff resources:
The Programme workforce is made up of two full time posts: A Public Health worker and a Senior Nurse in Manchester Mental Health and Social Care Trust. The two staff members work as a team with respective managers and clinical supervision. During the early work of the programme it was recognised that the Health Check Nurse (HCN) could not carry out her work without administrative support which has been loaned from MMHSC Trust. There was an overall agreement within the team that the administrative support was necessary to enable the nurse to manage her time most effectively visiting health check clients and giving input to the Health Improvement/Health Promotion strand of the work. A continuation in funding of the Programme would need to factor in this additional cost.

Partnership working with Trust:
The structure of the project although sitting within the Mental Health Public Health Development Service (MHPHDS) has had vital links including management and administrative support from within Manchester Mental Health and Social Care Trust. From the outset the project has developed a partnership model of working.

Steering Group:
The programme has been guided by a Steering Group that has included a range of stakeholders from within MMHSC Trust, NHS Manchester and from the Voluntary Sector, as well as one full-time carer. However it may be important to think creatively about taking the direction of the Programme forward through further involvement of people with dementia and their carers.

The two work strands:

The Health Development Work

The Health Check Service

Much of the first three months was spent building networks and promoting awareness of the programme and generating referrals for the Health Check Service. This enabled links across the city to be made and the service to be well promoted in terms of receiving referrals by the time that the Health Check aspect of the work began.

In our fieldwork, workers from allied organisations were sometimes not clear that the Health Check Nurse and Health Development Worker were part of the same project. Due to workload pressures the time spent working and planning together has become less regular. It is important for the project team to determine how they will apportion time to the different strands of the Programme and the resources, human and otherwise this will require.

Project Purpose:

Our evaluation has shown that the understanding of the purpose and the vision for the Programme varies within the project team to reflect each person's particular working responsibilities but there are overlapping features and perspectives within the team:

> Bridge**: The project is a bridge or a link between other services and people with dementia and their carers.**
>
> Partnership: **The project sets out to work in partnership with other organisations and agencies.**
>
> Enable: **It is an enabling project established to support and empower both people with dementia, their carers and other services working with these client groups.**
>
> Flexible: **It has a flexible model that allows it to 'parachute' into other services and work within their established structures to carry out its work. This is potentially one of the most important features of the project as this allows it to reach widely and also to develop lasting changes to working practice within organisations.**

Review of the Programme documentation

As part of our evaluation we also undertook a snapshot review of the service documentation using a randomised selection of case studies (see Appendix 1) and monitoring information drawing upon a grid of six indicators:

1. *Referral mapping: Looking at sources of referrals to the service and any changes to these over the period of the evaluation alongside referrals on to different providers and organisations following screening.*
   The referrals in our selected snapshot (see Appendix 1) show a variety of sources. There is a higher number of referrals from one care home (almost a third of our snapshot) due to extensive work undertaken with this home.
   In terms of assessing appropriateness of referrals there should always be a reason for the referral explaining why the person is referring on and what the person's needs are. The MSHP need to have clear criteria for what is an appropriate referral to ensure the most effective use of resources. It may also be an important development to spend time generating more referrals from primary care workers: GP's, District Nurse teams, as well as social care settings, where the teams particular knowledge and expertise can be well utilised.

2. *Coverage: Looking at geographical coverage of the service and the variety of different settings in which the screening service is provided.*
   In terms of geographical spread, the main activity of the pilot Programme has been in Central and North Manchester. This is possibly related to the

networks already established due to project staff's occupational history, and also linked to where they are based. The Health Check Nurse has been working with administrative support in North Manchester General Hospital. There are also clusters of organisations around Central Manchester that the Health Development team has been working with. The Health Development Worker explained that the team had also utilised existing networks established by the MSHP for people with severe mental health problems.

3. *Follow-up: Looking at the on-going support needs of service users and how these are met and monitored by the service.*
   The Health Check strand began some months ago to try to maintain rather than increase the levels of referrals that it accepted onto the programme due to capacity and concerns about project funding ending. The original target was set stating that the Health Check Nurse would visit patients 6 times, once per month. However in practice there have been inevitable lessons learnt: Some people in the Programme may present with a range of issues that require subsequent follow-up's more quickly and others less so. The programme has needed a more flexible, individualised approach which the Health Check Nurse was quick to recognise. The current approach for the programme is 6 visits within a 6 month period. However a great deal of the work is also about engaging care staff and enabling them to take responsibility for the identified health needs.

4. *Embedding and networking: Looking at the wider awareness of the service amongst health improvement providers and the links and collaborations introduced through strategic partnerships. Efforts will also be made to consider how and to what extent health improvement services and facilities have 'opened-up' to PWD and their carers.*
   The importance of the health development strand in raising awareness of the programme has been vital for the Health Check strand to enable it to make referrals to other services – and for them to be accepted. There have been particularly encouraging developments with primary care health improvement workers within the Health Trainer Service with the opening up of this service to people with dementia and their carers. A continuation of this type of engagement sits would sit well with the overall aims of the Programme.

5. *Impact and implications 2: Looking also at the health outcomes for service users, up-take of health improvement opportunities and changes to behaviour and routines linked to health*
   The service documentation for the Health Development strand of the Programme shows that it has reached a wide range of organisations across the sectors. The MSHP will need to focus its targets for the on-going development of some of these connections, such as in the BME community. However this is not to negate the usefulness of promoting the service and its aims widely to maintain a level of visibility.

6. *Good practice and future potential: Looking at the initiation by the service of innovative projects and potential for future initiatives that will support best practice in this area.*
   Future initiatives: Without doubt, the Programme has made some lasting links and inroads into the working practice of other organisations, sometimes as a result of fairly opportunistic networking.

   There are opportunities to start new activity groups now that the two pilot groups are established. It could also prove useful to make links with other organisations where good practice has been identified to enable a strong force for promoting the physical health needs of people with dementia, such as the cardio vascular specialist nursing team.

Work with stakeholders

Work with People with dementia

The Programme Plan identified 5 sub-groups of people affected by dementia and offered a rationale for targeting these groups. The Plan indicated that referrals would be prioritised using a triage system to ensure the limited resources available would be directed to the identified groups. The choice of the five groups, primarily those currently excluded from mainstream dementia services is linked to local and national policy and well supported by existing evidence concerning groups where physical health promotion would potentially have significant benefits. The Programme is also addressing health inequalities by highlighting groups that presently face significant barriers in accessing services. In relation to people with alcohol related brain damage (Korsakoff's syndrome) the Programme is targeting a group about which little is currently known but where significant benefits are attached to lifestyle changes given the potential to halt the progress of the condition.

The decision to target individuals with a recent diagnosis offers opportunities for people with dementia to take control of their health at a period of transition where currently levels of advice and support can be limited. Identifying BME groups and communities where vascular disease is known to be higher than the general population is also a sound choice for the targeting of resources given the links identified between conditions such as early onset diabetes, stroke and vascular dementia.

Evidence supports the targeting of the groups identified and given the limited resources available to the team these choices remain an appropriate focus. Our only question at this exploratory pilot stage of the Programme was whether the selection of mainly 'hard to engage' groups represented an additional challenge at such an early point in the Programme's development.

Key findings:

The Programme is already having a clearly evidenced preventative role in identifying potentially serious health issues through the screening process.

Our fieldwork uncovered 5-6 separate instances where the HCN had identified a potentially serious health issue and referred a service user on for specialist intervention. Examples included identifying the potential ingestion of an overdose of painkillers for a service user who was consequently admitted to hospital; suspected DVT in the leg of day care attendee; and high blood pressure for one service user during a home visit:

"Well the first time she (Health Check Nurse) came, I mean, she took his blood pressure and all that and his pulse and his pulse was very, very low, which it never had been, and his blood pressure was sky high, just out of the blue, and she immediately rang our doctors and got an appointment first thing the next morning…..So I said I could do with you ringing every time." (Carer)

In another example through promoting self-monitoring for testicular cancer in a care home for men, one resident was able to seek help for a lump and be successfully referred on and supported through specialist services.

These findings support an argument for the continuation of the Programme on economic grounds, based upon an 'invest to save' principle. The role of the Health Check Nurse (HCN) has facilitated rapid and appropriate access to health care in a timely fashion for people with dementia using the service. According to our scoping investigation, this intervention alone represents a significant change to current conditions regarding access to health care for people with dementia.

The Programme has adapted itself to the diverse and sometimes complex health needs of people with dementia, providing tailored support and advice.

The evaluation confirmed the diverse nature of the health needs of people with dementia which included many instances of co-morbidity as well as widely differing attitudes to health and accompanying lifestyles. The tailored nature of the health screening meant that advice and support was made meaningful at an individual level – for instance some of the interviewees compared the Programme favourably with the more impersonal health advice given out by GP's. It is likely that this more tailored support will have a greater impact on health behaviours over time.

We also saw evidence that the health promotion training was being adapted to take account of the differing learning needs and capacities of the various groups participating in the Programme.

The Programme is supporting a more positive self-image for many participants and its focus upon physical health provides a less threatening basis on which to build a relationship with service users.

The work of the Programme has also begun to reveal the benefits of a focus upon the body and physical health in the context of a deteriorative condition such as dementia. For some people with dementia that we spoke to the impact of the project had been to support either improvements to or the maintenance of their health out of which came a sense of being in control and in some cases a source of pride:

"Otherwise (from Alzheimer's) I'm alright, perfect everywhere. I've got a good pair of legs, I don't have any varicose veins, I've always walked [...] I don't smoke, I don't drink, I'm a good cook, balance vitamins in one thing and another"

These findings suggest that health promotion with people with dementia can open up opportunities for an alternative and more positive narrative of self and be a support to self-esteem and wellbeing.

People with dementia who live alone have emerged as a (further) distinct group targeted by the Programme.

The health screening service has begun to build a caseload of people with dementia who live alone, many of whom have limited support networks to provide informal care. An important finding from our work with people with dementia as part of this evaluation has been to understand how a person's sense of their body is altered when they have dementia. The capacity to self-care and to self-monitor is often compromised and in the absence of a primary carer this places single householder PWD at particular risk of emergency hospital admission and early admission to long-stay care.

In shadowing the HCN we saw evidence to suggest that despite the input of care and support from an interdisciplinary team for many of these individuals, their physical health is often neglected and there can be a failure to fully appreciate the interconnected nature of physical health and the symptoms of dementia within existing services. Additionally, a number of the PWD we spoke to revealed they were wary of discussing their health problems with practitioners due to fears they would be seen as unable to cope and this would lead to a loss of independence (i.e. through admission to long stay care).

These findings strongly support the continued development of work with single householder PWD and again this is an area that supports an economic rationale for the Programme given that early admission to long stay care for many PWD who live alone often comes as a result of physical deterioration and neglect.

Contributing to the evidence base for non-pharmacological interventions in dementia

Within national policy attention has turned recently to the importance of reducing anti-psychotic medication for people with dementia and finding alternative interventions to assist in symptom management (Banerjee 2009). This represents a significant opportunity for the Programme and a source of leverage when engaging

organisations that support people with dementia. In the longer term, the Programme is well placed to support this policy aim through introducing people with dementia to physical activities and health improvement initiatives. In so doing the benefits revealed may add to the currently limited evidence base for non-pharmacological interventions.

Work with Carers

Informal carers provide the vast majority care to people with dementia and existing research shows that a breakdown in the caring relationship is the primary reason for admission to long-stay care. There are currently 60, 000 carers living in Manchester and the Programme clearly holds the potential for learning that will be of benefit to this wider population of carers. As the Programme Plan highlights, the health of carers and hence their capacity to continue providing care has significant implications for the health and social care economy. The Plan identifies carers to PWD from the 5 targeted group as priorities for support and intervention. This decision makes sense if the intention is to work with caring dyads who are jointly recruited. However, the Plan has no obvious strategy for engaging carers in their own right according to need and we would ask whether the Programme may benefit from introducing criteria for targeting sub-groups of carers in a manner similar to the targeting of PWD.

Key findings:

Engagement of carers is still in the early stages and further development of this strand is required before it is possible to properly evaluate the benefits of the Programme for this group

The numbers of carers involved in the Programme to date and the level of their engagement is not as great as planned, especially for the health screening strand. There are various reasons for this that include the late start to the full Programme and the requirement to build networks for referrals in the early stages. Many of the carers we spoke to during site visits and interviews were already well known to providers such as the Admiral Nurse service and the Alzheimer’s Society suggesting that the intention to prioritise individuals who were excluded from existing provision had not been so well achieved with this group. Although recruitment of carers is still in its early stages something to consider for the future development of the programme is how to engage people who do not belong to existing groups.

Many carers put the health needs of carees above their own and this presents a challenge to directly engaging them

For carers whose commitments were round the clock in the support they provided to the caree many reported a neglect of their own health and related needs. Despite acknowledging how difficult it was to provide care when unwell, two interviewees stated that they felt they had enough to worry about in the health of the person they cared for to be giving thought to their own situation. This self-neglect was

compounded by the failure of some practitioners to pay attention to the specific health needs of carers. One interviewee reported that in the four years of accompanying the person she cared for to the GP, not once had she been asked about her own health at the same time. Their at times selfless approach to providing care is one reason why engaging carers may have proved a challenge for the Programme to date. However, this attitude revealed reluctance on the part of many carers to consider the longer-term implications of the neglect of their own health, not least in respect to their continued capacity to care. While forward planning is clearly a sensitive issue for many, in this respect the findings serve as an important indicator of the need for health improvement support and screening that targets carers.

The identity and purpose of the Programme were unclear to many of the carers we spoke with

Many of the Programme activities that engaged with carers were in the form of collaborations with other services and providers. However, a number of the carers we spoke to were unfamiliar with the name of the Programme (although they did recognise the name of the Programme staff) and others who had heard of the Programme were not aware of the health screening service aspect to it. Very few were able to describe the overall purpose of the Programme suggesting the need for a stronger 'branding' and the importance of highlighting certain core messages especially when working collaboratively with allied organisations.

Carers' attitudes to health and efforts to maintain or improve their health are not homogenous

During the evaluation we heard from carers who had been health conscious and physically active much of their lives and where caring commitments were gradually eroding opportunities to maintain that level of activity; also to carers who had used their caring role as an opportunity to improve their health and that of the person they cared for; and others who had sometimes serious complicating health problems that compounded the challenges of providing care. Such variance underlined the value of a tailored form of health support and promotion. Almost all carers talked of the impact of stress but many dissociated this from their health, describing it as a separate issue, thereby highlighting the potential benefits of promoting a more holistic model of health with this group.

"Well I am healthy, well I have blood pressure problems and I take a cholesterol tablet but apart from that you know I'm healthy. It's just a state of mind I think really, just stress [...] Well, I'm drinking more, you know, I admit that and I know I shouldn't and I do try to hold back and then I think what's the point? You know, what else can you do when you're so wound up?"

Many carers revealed during interview the negative coping mechanisms for dealing with the stress of caring and the Programme has responded to this with initiatives that promote wellbeing alongside physical health

The interviews with carers revealed the interconnected nature of mental and physical health and emotional wellbeing. Some mentioned that they had been prescribed anti-depressants while many others admitted to drinking alcohol, over-eating/comfort eating, smoking and in one case self-harm as ways of responding to the stress they were enduring for prolonged periods. We asked carers to tell us how they felt about their bodies and many reported negative feelings about themselves and few opportunities to engage in activities that made them feel good about themselves.

- *"And in terms of making yourself feel good about yourself, what are the things that you do?"*
- *"You're looking at me aren't you! Very little, very little. Feeling good about myself? If you carry on along this line I shall probably end up in tears, because not a lot really. I suppose the highlight of my entire month is the support group."*

It was clear that for some a poor body image provided a context for the destructive coping mechanisms described above. The emphasis within the Programme upon 'feel good' physical activity such as introducing dance classes to carers groups is very appropriate given such evidence and further developments along these lines may well support greater levels of carer engagement. A focus upon body image may provide a starting point for work with carers in supporting them to feel good about themselves and as a route to improving their health.

Carers valued the group sessions as sources of support and sociability and many had suggestions for how the groups might be developed

Success to date has been shown in developing group activity where people can take part in a healthy pursuit, engage in health improvement training and be with others who share similar experiences. The findings from interviews with carers attending those activities suggest the highest value being placed on acceptance, shared experience and an opportunity to take time out from caring responsibilities.
Some carers mentioned that getting out and about in public spaces was difficult due to the unpredictable nature of the carees conduct and the stigmatising response of others. For others, the physical impairments or limitations of the person they cared for curtailed trips outside the home.

"I always thought…because I'm fifty eight now, and I, kind of, thought when I was younger I'd be in my, like, twilight and I'd be hiking and I'd be doing things like that and it is limiting because even when my mum's away I'm still limited to what I can do on my own but, yeah, I'd love to…I'd love to, like, join a rambling club and go out on the moors for a whole day."

In terms of people with more progressed dementia it was difficult to disentangle their health from that of their carer. The important role of the carer in monitoring their loved ones health pointed to the value of including carers in efforts to support the health of the person with dementia.

Many carers reported that dementia specific events such as cafes and groups were their only opportunity for social engagement and support. While the more formal

health talks and lectures offered by the Programme appeared less popular the interactive activities that combined social interaction with physical activity or learning appear to be a successful mechanism for the engagement and retention of carers. All the carers we spoke to were clear about how they would like to see the groups developed and organised. For instance, many highlighted the value of organising groups in ways that temporarily relieved them of their caring responsibilities in order to better engage in the activities to hand.

These findings point to the value of greater levels of user and carer involvement in the management and provision of the Programme and offering increasing control for carers over format and content.

Work with Allied Organisations

The Manchester Supporting Health Programme has worked with a wide range of organisations, with varying levels of contact (following on from initial networking). The work of the Programme has been organised around two main types of activity for health promotion i) raising awareness of physical health with dementia providers ii) raising awareness of dementia with other health providers and frontline staff. 'Mapping' of community resources to promote the wider participation of people with dementia has also been developed by the Programme and represents a valuable resource that could be made available more widely to those involved in dementia care.

Key Findings

Social Care Settings

"It's a stone in a lake; you drop it in and the ripples [flow] out to hit everything"

In-depth and integrated working by the team has led to the prospect of sustainable change in social care settings. There also seems to be a high value in targeting social care settings where there is limited dementia health care expertise.

The health improvement strand of the programme has been particularly successful when working together with the health screening strand. For example in one care home setting, the health development strand has acted to deepen the work of the health screening programme by embedding the physical health needs and health improvement ethos in the service practice.

"As part of our business plan this year, and again because of this project, we've made health and well being one of our objectives for the year. We've got the staff involved in a health plan, that the organisation pays for now, about…around glasses and dentists and opticians and all them things so that that's paid for, for the staff now. We're encouraging the staff, as many staff as possible to take part in these healthy living sessions with the men. You heard one of the men say that he wants to learn how to swim. That also highlighted at that session, we've got about four staff that can't swim so we're now going to try and encourage them to take the same lessons as the men when we do get that going. So it's had a massive impact, at the fun [sports] day that we had yesterday,

everyone realised how unfit the staff are as well as the residents, so yeah again, it's like ripples in the water, it's had a real knock-on effect."

The service users have also engaged well with the health check strand of the work and the care home manager suggests that this is often not the case for some of the residents,

"Well, well some of these residents just will not go for that appointment so without [the health check nurse's] intervention, then they wouldn't have got the health….the physical health checks that they need"

The work here with both strands of the Programme has been able to engage in education through which it has developed the understanding of the importance of health promotion and health improvement activity amongst staff and the service users. In turn this has led to success in engagement in the preventative and health maintenance aspect of the Programme.

The Programme has operated flexibly to adapt itself to the differing needs of stakeholders

The ability to work flexibly and in a home-focused way has enabled positive improvements to working practice in addition to establishing relationships with a client group that often does not engage easily with services.

A clear message from one care setting concerned the benefits of the MSHP workers coming to them. The fact that the MSHP staff spent time at the care home, getting to know the staff and the residents; delivering the learning and information sessions on-site; and being flexible with the session structures enabled a strong rapport to be built between the care home staff, the residents and the Programme workers:

"we're a care home, from our point of view, we've never really had a professional that's come in, that's been very sort of home focused and which [health check nurse] has been….from our point of view, this is the first opportunity we've really been able to work with somebody, that can be on site, that can come in and hold clinics"

This for care home managers must be a strong positive of this Programme as it will impact far less on staff resources for staff leaving the residential setting to attend training or to take residents to meetings and appointments.

The HCN also carried out training on a weekend to adapt to the needs of the catering staff at the home, showing great commitment to flexible working, ensuring a whole team effort throughout the residential home to understand the residents needs and to promote physical health messages,

"So that's been really, really valuable to us….[I. Yeah, that's great isn't it? Because normally non-care staff just don't get any kind of training do they?] No…we've got a hundred percent training of all our catering staff and of all our care staff, and all our housekeeping staff as well. So everyone here has had, one way or other, some very valuable training".

Allied organisations have benefited from the sharing of expertise and knowledge by the team

In terms of developing the knowledge of the workforce it was not only through training sessions that staff benefitted but also from having a dementia health expert alongside them modelling good practice. The programme has also provided another line of support for the organisations engaging with the scheme. A care home manager explained how the Health Check Nurse's expertise enabled the home to continue to provide care for one resident who might otherwise have moved to a more secure environment

"We were really struggling with one resident, we hadn't got enough experience on-site for our staff to understand how to deal with somebody in this situation and I was very near to saying we couldn't support him at the home, and it has been really beneficial that he had remained with us. I think without [HCN's] support, that wouldn't have been possible"[...] "from people being with us here to needing more care, means like a supportive environment, like a lock-up environment and that costs... the cost involved in that type of placement is probably over double what it costs for this type of care"

In two social care settings staff talked about the importance of having the medical expertise of the HCN. They described how empowering it was to have someone listening to them but also helping them to take good care of their clients,

"I think it gives you more, is ammunition the right word? It just gives you more confidence really to be able to say well, oh right, yeah, I know how to, you know, I know how to deal with this now. You know, I shouldn't have been doing that, and maybe this is the right approach now, you know. We can go down a different road now. And then we might be able to interact a bit more, you know"

In another social care setting they also described having someone with dementia health expertise as "lending more weight". This is a very positive message from social care staff in terms of how they benefit from having a medical professional working alongside them in this way. One person stated

"She might just ask whether their sleep was broken or she might just say have you been having your breakfast, or she might say...the list goes on. And it's stuff that I think that I know, but when I'm listening to the questions it's identified to me that I don't know really, I'm just assuming that I know and I know that we should never assume.....and it's little lessons like this really that for staff she [HCN] puts over wonderfully"

Staff in the settings supported by the MSHP now feel that they can take health issues forward as they are supported by a health professional. In addition, staff describe improving their own working practice through working alongside the HCN.

This evidence provides a clear indication of how the MSHP is succeeding because of the specialist knowledge it can provide. This is in line with the All Party Committee on Dementia's report which makes a key recommendation that the health service

should share it's expertise with social care, (All Party Commission, June 09). We view this as an exemplar of such an initiative.

The Programme has started to promote 'joined up' working to strengthen the networks involved in dementia care

In the care settings where both strands of the Programme have been actively involved, links have been established with outside agencies engaged with health improvement work. The residents of the care home discussed above have all received assessments for involvement in the Physical Activity on Referral scheme. They have also had input from the Health Trainer introducing new activities to the residents. A member of the management team observed that it is this kind of working alongside other agencies that will ensure long term impact for them.

The Programme has enabled staff to further their knowledge of dementia and to understand the behaviours of their client group. It has developed the understanding of the importance of health promotion and health improvement activity amongst staff and the service users.

Voluntary Sector

The MSHP has been able to engage with voluntary sector organisations through offering health improvement opportunities to service users and carers; through offering training; and by linking organisations up with other allied health workers such as the Community Health Trainer Service. They have also made contact with many organisations for initial meetings raising awareness about the Programme and possibilities of future work.

The Programme has facilitated new initiatives around health improvement

The Programme has been able to support new health improvement projects to become established with financial resources, shared expertise and with the provision of information and training. Our evaluation findings suggest that these are planned to continue beyond the initial MHSP funding enabling the programme to move on to develop other projects in target areas. One healthy living group activity has engaged the Community Health Trainer who has now submitted a proposal to her team to continue a dementia dedicated dance group.

The building of links and relationships with Black and Minority Ethnic Communities is still in the early stages and points to the value of developing longer-term strategies for different communities

There is an identified need to engage further with Black and Minority Ethnic (BME) organisations and service users.

Although the programme has received some referrals to the health check programme for individuals who are from BME communities the numbers are low, and are not always from the targeted groups. The Programme has engaged with a number of voluntary sector organisations and with Manchester Community Development Workers. This work has included some awareness training and also attempts to develop an acupuncture project.

There is value in having a knowledge-exchange approach with allied organisations and including workers from these organisations in planning with the Programme regarding how information is delivered and the approach taken. The evaluation highlighted that much expertise regarding cultural competence in working with different communities exists within these allied organisations. Many of these organisations may already be undertaking health improvement work. It is important for the Programme to think creatively about how to tailor their messages of health promotion and health improvement.

Other Allied Health Workers

The programme is building bridges between services to enhance capacity around dementia within and across different sectors

The development of work with the Community Health Trainer Service has been very positive in engaging the Trainers with other organisations in the voluntary sector and social care.

The MSHP has also provided some training and is planning more for this service to enable them to feel more confident about the inclusion of people with dementia and carers in their service. Again it is this working together of the two strands of the MSHP that helps to ensure that thinking about people with dementia and their physical health is embedded in working practice through the development and sharing of knowledge, expertise and resources. The ability for the Manchester Supporting Health Programme to be flexible and innovative in their work with other organisations has been a contributing factor in making collaborations work.

Following an initial stage of awareness-raising and networking the Programme has gained in-roads to General Practice and is currently fostering relations with GP Practices.

The development of relationships with GP Practices is in itself an achievement for a Programme of this nature and some Practices have shown themselves very receptive to joint working with the team. There have also been occasions when the team have challenged instances of inappropriate care and negative attitudes towards people with dementia.

Given that GP's play such a crucial role in the healthcare of community-dwelling people affected by dementia there is a clear argument for strengthening of relations

with primary care. We see benefits to further developing the work alongside primary care health workers and health improvement workers, possibly extending to include district nurses and practice nurses.

Overall impact of the Programme to date

We see this pilot Programme as providing the foundations for an effective and timely long-term initiative and as a necessary precursor to seeing a range of tangible outcomes and impacts which can only be fully appraised over an extended timescale. However, we are able to gauge at this stage the early indicators of preventative health care and health promotion developed through joint working and innovative practice. And, in some cases the potential for radical change and improvement to current provision for people affected by dementia in Manchester.

An economic rationale for the Programme

Under current conditions it is clearly important to understand the economic implications of the Programme and there are three key questions that might assist in judging this:

- Is the Programme reducing levels of uptake and demand on other services?
- Is the Programme preventing the need for more costly interventions and provision by helping to avoid critical and crisis referrals?
- Is there evidence that the Programme has made a cost efficient use of the resources available to it?

The first of these questions is difficult to answer at this early stage and on the basis of a small-scale evaluation. However, in developing health improvement groups and support groups for carers the Programme has promoted levels of peer support that offer a preferred alternative to accessing formal services for many of the carers we spoke to creating opportunities for other forms of support and consultation. Many carers also stated that their first point of contact if they had a health concern were now the staff running these groups. In the longer term, the work undertaken by the team to map community-based resources and promote access for people with dementia is also likely to have a beneficial impact on current demand on dementia services.

As discussed above we have found early indicators of the preventative nature of the health screening service. Our scoping work suggested that many people with dementia present late on with physical health conditions and the introduction of the Programme has led directly to more timely and appropriate referral to health services. Intervention by the HCN has also helped to ensure a rapid and appropriate response from these services. The work with single household PWD also holds the prospect of reducing untimely admissions to long stay care. The tailored nature of the support on offer from the Programme may also prove over time to be more effective in altering unhealthy behaviours and in reducing negative coping strategies.

The well-informed selection of sub-groups targeted by the Programme offers good evidence of the cost efficient use of Programme resources by directing resources where need is high but also where physical health promotion is likely to have significant health outcomes. The introduction of administrative support for the team has also meant the time and expertise of the two workers is now spent in a more appropriate and cost-effective manner.

Tackling health inequalities

A concern to tackle health inequalities lies at the heart of much welfare policy at present and represents a significant challenge at a local level for Manchester health and social care services. In the work undertaken with different providers the Programme is challenging discrimination towards people with dementia and the stigma attached to the condition that has caused the needs of PWD to be neglected by many mainstream providers.

"Initially the GP was quite negative and he said, 'she's got dementia, she's probably going to die, let's just let her go'. And I expressed my concerns about that, that we really needed to support her with all the interventions that we would with somebody who didn't have dementia and the fact that she had dementia should not come into the picture at all."

The decision to target resources at groups well known to be excluded from mainstream health services reflects policy on health inequalities. The Programme is supporting rapid and appropriate access to help and support for groups such as long-term homeless men, where the uptake of health services is known to be low and where much distrust exists towards service providers. For such groups the effects of these inequalities are entrenched; the long-term neglect to health and the impact upon both physical and mental health incurred due to homelessness and alcoholism represent significant barriers to rehabilitation. However, the evaluation has found that in-depth, co-ordinated and tailored work by the Programme with particular care providers has proved a successful recipe for change. These early successes provide a template for further work and the challenge ahead will be to replicate these early achievements in comparable settings.

The Programme is serving as a catalyst for sustainable change in dementia care

A crucial question for the Programme concerns the sustainability of the changes it has brought about. This is something best measured over time but early indicators include existing organisations taking ownership of initiatives introduced by the Programme and changes occurring at the level of local policy.

The health improvement strand of the programme has successfully supported the development of projects alongside Admiral Nurses and within the voluntary sector. These sessions have included health improvement training, awareness-raising sessions, and opportunities for dance, walking and other forms of exercise. They have also

provided access to alternative health practitioners, and the Health Trainer Service amongst others. The Programme has been able to support projects with financial resources, shared expertise and with the provision of information and training. Our findings suggest that these will continue beyond the initial MSHP funding enabling the Programme to move on to develop other projects in target areas.

The Programme has worked strategically to bring about change that includes encouraging providers to include physical health in their business plans and to develop strategies for health improvement:

"So a lot of other things have fallen into place like the Mental Health Trust developing a strategy and policy for people's physical health and making sure that it's embedded in the electronic patient record system and all of the staff training and having a staff network for physical health and having key contacts throughout the services who are interested in promoting physical health"

The empowerment of stakeholders

The health screening service has enabled people's health needs to be addressed where they might not have been identified. This has worked in a number of different ways in terms of empowering carers, people with dementia and staff.

It has been empowering for people with dementia themselves who have been able to be supported to engage with their own physical health through self-monitoring their diets and checking for health problems, such as testicular and breast cancer. Also, through training delivered to people who are newly-diagnosed.

One example is highlighted by the residents of a care home who requested changes in their regular meals in order to include a lighter meal option in the evenings on the menus. This was a result of the Supporting Health Programme, which identified diet and nutrition as an important area of concern.

It has also provided more substance to requests for support with health problems through having a health professional backing up referrals and this has ensured a rapid response to a problem where needed. The Programme has both revealed and challenged a tendency for physical/bodily neglect in many areas of mental health provision.

In the longer term, efforts to map available services and resources for people with dementia in the community and to promote greater levels of social participation is supportive of PWD and carers taking greater over how and where they seek support.

4. Looking ahead

Challenges in taking the project forward

The Programme faces four broad challenges as it develops beyond the pilot stage

Funding - Uncertainty over funding has had various implications for the Programme, not least in hampering efforts to develop longer-term planning and strategies for the work ahead
Coverage – The size of the catchment area for the project points to the value of considering additional approaches to communicating with stakeholders and development of more 'arms-length' forms of support and advice
Demand – The number of individuals eligible for support from the Programme is clearly greater than current capacity with the potential for a bottle-neck of referrals creating pressure on the service. The team face the prospect of seeking to further develop aspects of the service to take account of this demand or strengthening the eligibility criteria for referrals
Need – The health needs of service users are diverse and at times complex, as the Programme develops there is potential for tension between the numbers of people accessing the service and the tailored nature of the service currently on offer.

In light of these challenges there are two key questions for the Programme team to consider. Firstly, the relative merits of breadth versus depth in their style of working (i.e. limited contact with larger numbers of stakeholders or more in-depth working with fewer recipients). Secondly, whether to place emphasis upon developing the Programme as a distinct service that addresses a clear gap in current provision or by operating in a more strategic fashion to promote a message aimed at bringing about change in existing service delivery.

5. Recommendations and conclusions

Drawing on a realist evaluation approach, we have considered how the Programme is working, for which groups, and in what ways it is working. In addition, we have also offered some specific insight into our fieldwork with carers and service users engaged with the Programme. In this final section we offer recommendations for future working based upon the findings of the evaluation.

Producing outputs

Given the challenges identified above regarding the geographical coverage of the project and the potential level of demand for the service we would recommend that the team devote time to developing certain outputs from their work that can be shared more widely. These might include

i) Developing a web presence where some of the core messages behind the Programme are set out alongside advice and guidance
ii) Developing and piloting tools that might be used more widely in dementia care. For instance the HCN has identified a need for a more tailored physical health check assessment tool for dementia
iii) Sharing resources developed by the Programme – for instance by formalising the community resource mapping process as an output from the health promotion strand

iv) While there are many available sources of advice and guidance on improving physical health there is a potential role for the Programme in developing briefings that give specific advice on physical health and dementia

Developing targeted strategies

Where there is the prospect of longer-term work with particular groups or communities we would recommend the development of specific strategies that take account of the particular needs and characteristics of these groups. For instance, there are marked cultural differences within the varied BME communities of Manchester both in terms of physical health needs and the understanding and attitude toward dementia. There is value in having a knowledge-exchange approach with allied organisations and including workers from these organisations in planning with the Manchester Supporting Health Programme how information is delivered and the approach taken.

There is also a potential role for the Programme concerning dementia and physical co-morbidity. The evaluation revealed that as dementia progresses the interaction with physical health conditions can create complex levels of need that mainstream service are ill-equipped to support. For instance, one carer described the failure of her husband's diabetic support service to advise on how to manage diabetes in the severe stages of dementia. Given the expertise within the team there is an opportunity to target more complex cases as another focus for referrals.

The project team may also need to do further work to ensure that they are not duplicating work already offered by other services/agencies, such as the dementia awareness training. Where dementia awareness training is offered by the Manchester Supporting Health Programme we suggest it should be part of a tailored package of work being undertaken with an organisation to develop its workforce and approach to holistic healthcare. There are other allied health workers that the programme has engaged with to plan and deliver training and it will be vital to ensure they are working with organisations towards a holistic health model of care. It is vital to the cost efficiency of the Programme that it does not duplicate work and maintains clear boundaries around all work undertaken.

Increasing levels of user and carer involvement

We feel that one area for future development of the Programme is a need to extend and formalise the involvement of stakeholders as an on-going feature of the project and to ensure that it can reach the gaps in service provision. The development of a more co-productive approach to service delivery could support users and carers in having greater levels of control over the way the Programme develops. It may also lead to service users taking ownership of the health improvement initiatives leading to greater sustainability.

Our interviews with PWD and carers highlighted that health improvement activities that provide opportunities for 'biographical continuity' are often the most meaningful given the way that dementia can be so disruptive to people's lives. Using biographies

and life histories to tailor activities may strengthen the impact of the health promotion work of the Programme and support engagement and retention of 'hard to reach' groups.

Branding of the project

Based upon the findings of the evaluation we recommend that the team consider strengthening the Programme 'brand' in order to ensure that the core messages and principles are better communicated to potential participants. The current project name 'Manchester Supporting Health Programme' is not well established even with current service users and the collaborative approach to developing initiatives with other organisations has led to the identity of the Programme sometimes being lost.

A strong identity will heighten visibility and presence for the Programme and ensure that it stands out from generic service provision helping to build networks and opportunities for future partnerships both within Manchester and beyond.

Developing a brand could also provide opportunities for user and carer engagement and promote a sense of ownership over the Programme as a whole.

Integrated working

One intention for the evaluation was to identify the most effective and successful mechanisms developed by the Programme. From the evidence so far, we recommend that the team should focus upon providing a co-ordinated service where both strands are integrated as this two-tier system appears to have most impact: working with service users and carers to promote their health and well-being; and to develop and train a Service's dementia expertise and knowledge to continue and deepen the work.

An emerging holistic model of dementia care

From the findings to date there is a clear message emerging from the Programme concerning the value of an holistic understanding of health and well-being. On many occasions throughout the evaluation we saw instances of practitioners working in particular silos, focusing upon aspects of health most relevant to their profession but failing to grasp the interconnectedness of the different components of health and wellbeing. Indeed, the Manchester Supporting Health Programme has served to expose the artificial barriers that exist in the delivery of support and care to people with dementia alongside the sometimes poor communication between different services and professions. By contrast, in the work of the Programme we see the early signs of a more holistic response to the needs of people with dementia that takes full account of the overlapping nature of physical and mental health.

Turning policy into practice

Manchester has outlined its intentions for the next three years to meet the needs of the growing numbers of people with dementia. The Manchester Mental Health Commissioning Strategy has prioritised people with dementia and is working to implement the objectives of both the Manchester Dementia Strategy and the National Dementia Strategy, (Manchester Mental Health & Well-being Commissioning

Strategy, 2009). It aims to improve the range and availability of services for people with dementia and carers; to adopt a strong emphasis on each person's life fulfilment with access to community support, dietary and fitness coaching and advice, and support to carers, friends and relatives. Manchester will adopt a 'recovery model' that has at its core:

> Finding and maintaining hope – believing in oneself; having a sense of personal agency; optimistic about the future.
> Re-establishment of a positive identity – finding a new identity which incorporates illness, but retains a core, positive sense of self.
> Building a meaningful life – making sense of illness; finding a meaning in life, despite illness, engaged in life.
> Taking responsibility and control – feeling in control of illness and in control of life.

According to these objectives the work of the Manchester Supporting Health Programme for People with Dementia and their Carers represents a timely, innovative and cost-effective programme of work that directly supports mental health policy for the City. Of particular significance is the Programme's potential to assist PWD to feel in control of their health and to support the re-establishment of a positive identity in the context of a deteriorative condition.

References

Banerjee, S. (2009), The use of antipsychotic medication for people with dementia: Time for action. Department of Health. London: The Stationery Office.

Goodchild, C. (2009) Living well with dementia: a national dementia strategy; joint commissioning framework for dementia. COI for the Department of Health. London: The Stationery Office.

Manchester Dementia Strategy. (2009) Manchester City Council Item 8, Appendix Health and Well-being Overview and Scrutiny Committee 21 May 2009.

Manchester Mental Health and Well-being Commissioning Strategy. (2009) Manchester City Council and NHS Manchester.

Pawson, R. and Tilley, N. (1997) Realist Evaluation. London: Sage

Prepared to Care: challenging the dementia skills gap, (2009). All Party Parliamentary Committee on Dementia. London: The Stationery Office.

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