**IDO SERVICE – WORK PACKAGE TWO**

**SESSION SEVEN**

**IDOSERVICE: AGE UK SALFORD – CO-DESIGN GROUP**

**15 March 2022**

*These contemporaneous notes were written by the four Manchester Metropolitan University researchers present, made on afternoon 15/03/22 and 16/03/22 and then combined into one document.*

We arrived at Age UK for 11.45 to set up. [STAFF 1] from Age UK welcomed us. We arranged tables for four groups and got materials ready to be distributed to participants / the tables. including post-its, pens, name labels, digital or Instax cameras to take pictures as applicable later. [STAFF 1] laid out lunch and prepared the beverages.

People started arriving just before 12noon and clustered around three tables, with more arriving a little later occupying the fourth table. There was one group with 6 people (table 1, facilitator: Laura, participants: 2 female, 4 male/ 2 PWD, 4 carers – including 2 former carers), another table (table 2) with 4 people (facilitator: Kristina, 1 male, 3 female/2PWD, 2 carers), one table (table 3), with 5 people (facilitator: Steve, 4 male, 1 female, 1 PWD, 4 carers), and one table (table 4), with 6 people (facilitator: Isabelle, 3 male, 3 female/3 PWD, 3 carers – 1 man and 2 women).

People had lunch, and towards the end of lunch time, we offered the consent sheets, which they signed helped by others in the group. People in the group had participated in research activities before and were familiar with signing consent forms. We answered any questions arising. When ready, Isabelle gave people the handouts for the introduction and made the introduction to the project.

We then worked in the four groups introducing and discussing the two graphics about the I do Service, using the additional circles to introduce suggestions for the service, and asking questions about participants’ experiences of their dementia journey and services.

**Group 1: (Laura)**

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| --- | --- | --- |
| Pseudo | Gender (male/female) | Role (PWD/carer) |
| [P55] | Female | Carer |
| [P54] | Male | PWD |
| [P28] | Female | Carer |
| [P25] | Male | PWD |
| [P26] | Male | Former carer |
| [P27] | Male | Former carer |

Group one consisted of 6 participants, 2 female, 4 male and the facilitator. Two persons had a dementia diagnosis and two were their carers (wives). Two participants were previously carers but their wives had passed away. They continue to come to Dementia Café for the friendship and to support friends they have made. All appeared to be in their seventies, eighties and nineties. One couple were new to the group, did not attend the November workshop and did not previously know the others in our group, but seemed to bond well. The others knew each other well. The two participants with dementia were chatty when spoken to, but their carers largely answered all questions for them. [P54] still rejected his diagnosis.

When asked about their pathway through diagnosis and beyond;

Pair one ([P55]/ [P54]): Attended a GP who referred to MAS. From MAS they felt they were somewhat abandoned. They felt the GP ‘didn’t want to know’ and the MAS didn’t follow through with their 6-month review until after 2 years later. They found Age UK by word of mouth and have only just joined this Dementia Café. They were very disappointed with the NHS treatment they had received but wanted to stress that the charities such as Age UK had been great. They didn’t know about social prescribers or many other services but found today very beneficial as they found out about the Carers Assessment for money, Blue Badges for parking and Humphrey Booth charity from the other group members!

Pair two ([P28]/ [P25]): Attended GP who dismissed [P25] as having depression. It took multiple visits before a referral was made to MAS. (He was also diagnosed with Parkinson's at a similar time so also went down a second pathway with a Parkinsons support worker so some support came from there rather than from the dementia pathway). Attended MAS who referred to Humphrey Booth charity. Also received a Social Worker who did an assessment but they never heard back what the result of that was. They were also referred to the Gadam Society but not sure if this was because of the dementia or the parkinsons. [P25] had no social prescriber / memory advisor. They agreed that word of mouth was key to the support they had received and had learned a lot through [STAFF 1] @ Age UK.

Participants [P26] and [P27] went through the journey a considerable time ago with their wives so had little recollection of the exact pathway but agreed they started at the GP and went to MAS from there.

The group unanimously agreed that a wellbeing mentor would be an ideal solution to some of their largest difficulties in navigating the system which [P55] described as “wading through treacle”. However, they felt this was more for the benefit of the carer rather than the PWD as it is the carer who needs to navigate the pathway and needs more help than is currently available. Someone who can talk through all the support available, all the benefits such as carers assessment, blue badge, Herbert protocol etc.

When asked about what a Wellbeing Mentor should do;

No one in the group had previously seen This Is Me or the GMCA wellbeing plan. They liked This Is Me and felt this was a good idea for anyone with dementia.

There were split opinions as to if a wellbeing mentor should do a skills audit 1-2-1 or in groups. Participant [P26] felt one to one would be more successful and relevant. Participant [P27] felt group work was more likely to spark ideas. Pair [P55]/ [P54] and [P28]/ [P25] agreed they liked listening in groups but felt happy on an individual level also.

They felt that a game or exercise to explore available meaningful activities was overcomplicating something that should be just simple outright questions to a PWD.

[P26] felt a PWDs mind would wonder if it was too abstract. They also felt the approach should change based on the stage of dementia, as everyone in this group had experience of dementia being diagnosed late when this was already no longer relevant.

Similarly for the idea of a skills fair – it would be useful but only at an earlier stage of dementia. A regular fair would not be feasible to those who cannot plan that far ahead.

[P27] stated that in his opinion for a wellbeing mentor to be effective, they would have to have to be available to support a PWD 24/7 and not just in office hours, as the hardest part of being a carer is when all the help stops in the evening and throughout the entire night. He felt that currently, the people he had experienced who work in any form of dementia related support only had textbook knowledge and not real life knowledge, so they didn’t understand the horror of not sleeping for days, locking doors inside the house to prevent wandering, night crisis and therefore the support was quite superficial and without real understanding. He would like to see a round the clock support mechanism as part of the wellbeing mentor role.

He and [P26] both agreed that previous carers who’s partner had passed away were the ideal sort of candidate for being involved in volunteering since they had that level of understanding that people without first hand experience can’t learn from a book.

**Group 2: (Kristina)**

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| Pseudo | Gender (male/female) | Role (PWD/carer) |
| [P38] | Male | PWD |
| [P39] | Female | Carer |
| [P36] | Female | Carer |
| [P37] | Female | PWD |

Group two consisted of 4 participants, 3 female, 1 male and the facilitator. Two persons had a dementia diagnosis and two were their carers (daughter, and wife). All appeared to be in their seventies or older. All knew each other well and observed that they were very glad to be back and able to meet together in such a large group. When the group returned after the Covid restrictions were lifted, only groups of six participants were allowed.

Kristina explained the first graphic as being a generic representation of the dementia services, and mentioned each part. Co-design participants discussed the connections between them and their experiences:

**Pair one ([P38]/[P39]):** had been referred by their GP to MAS, then sent home from there with advice to contact Age UK Salford, who they were very happy with. However, their experience with the GP was negative in that they did not find the GP helpful and did not seem to be aware that they had been referred to MAS until a letter arrived.

**Pair two ([P36]/[P37]):** had been referred by their GP to MAS, then had contact with another person, possibly from social services – they were not quite sure, but who might have been a social prescriber or similar – and who recommended some activity (singing group) who they went to and were very happy with. From there, word of mouth through other group members was the most important way of finding further support.

They mentioned a number of examples of successful support they had received subsequently:

* doctor in church at the back of Liverpool Road in Salford activities included making pots and painting tiles; activities took place in the garden; vegetable soup was provided because it is easy to make in bulk
* they mentioned the singing group that started them off
* they found out through the minister
* The Henry Brook Centre in Salford run by Aspire was another example

Now, some time after the diagnosis, [P36]/[P37] fill much of the week with activities such as:

* Monday morning zoom for music
* Tuesday Age UK
* Wednesday morning singing and dancing for dementia
* Wednesday afternoon curling
* Thursday morning Domino and Bingo session, which [P37] is good at and often wins
* Thursday afternoon armchair aerobic

[P38]/[P39] said that he likes walking and cycling. They also go to the Betty lunch and bowling at Liverpool Park in Salford.

Both pairs agreed that information provided at the time was insufficient. Neither did they know what a social prescriber was or whether they had seen one. They agreed that the pathway is different (e.g. GP/MAS/GP or GP/MAS/dementia organisation) for different people, and that a Wellbeing mentor would be useful to find out what people might like to do. They felt that everyone should have a wellbeing mentor/social prescriber.

They thought that having a group session first with an individual session as a follow-up would be best, and that they had experienced something like it when they joined Age UK.

They felt that the info was not sufficient and there was nothing about confidence building. And that they needed to be something to encourage people.

They felt that at the group session would provide peer support, ideas and confidence, while an individual follow-on session would enable a more detailed discussion about aspirations and needs regarding support.

They felt that accompanying support also for the carer was very important otherwise carers feel isolated. For example, one of the staff from age UK Salford called [P36] when she was ill with Covid.

Other care initiatives included: a half hour drive in the car making the person with dementia feel that they have been somewhere, and that they have not been stuck in the house. It was felt that the more social interaction they had the better.

They suggested we should speak to the early onset group they are still working and would be very interested in this and that they might help as volunteers. They gave one example of a person with dementia recently diagnosed who provides peer support.

They observed that age UK groups provide a safe space. People need a lifeline. They need to find something for five days a week. They found that the first time is daunting. They need someone to support and encourage them. It’s all about joining in and meeting people.

Further activities and volunteering help they mentioned:

* Dancing for dementia at Swinton Palace.
* Birthday presents for people living alone in a home by school children. They said it could help people who live alone who have no relatives or friends to send them cards or presents.
* They once received a Christmas card from a school child. The child was 10 or 11 years of age. In the letter it apparently said that adults think that children don’t know what’s going on but that they felt that they knew that they watch the news.
* They talked about the fundraiser to help set up relevant groups.
* Somebody called [NAME] volunteering with the early onset group.

With regard to the volunteer/skills service, they felt there should be a mixture of go to groups they visit and volunteering groups where you offer help.

[P37] thought that the volunteer taxi would be great even have to have to pay a little but that taxi these days is so expensive. We talked about other volunteering activities such as Tall Ships for disabled children or children with cancer.

Having a group to go to is important, too. Because they can speak to other members in the group to find out what they do and to help them discover something new even things that they thought they never wanted to do.

They were happy with a taster session with volunteer services, having a choice between going there, and them coming to the wellbeing group. Having a choice is important.

**Group 3: (Steve)**

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| --- | --- | --- |
| Pseudo | Gender (male/female) | Role (PWD/carer) |
| [P33] | Male | Former carer of [L] |
| [P30] | Male | Former carer of [C] |
| [P31] | Male | Former carer |
| [P51] | Female | Carer for [P50] |
| [P50] | Male | PWD |

For the start of the session, the group reflected on the discussions and topics of the previous engagement session in November, revisiting the group’s experience of activities and shared interests through organised days and events for people with dementia - including:

* Days out (i.e; Blackpool)
* Visits to pubs and restaurants
* Dog walking
* Book clubs

Elaborating on the book club, **[P30]**  highlighted how conversations around book readings trigger memories and reminiscences

1. **Service User Journey**

The group gave individual experiences of service at points of diagnosis and memory assessment:

**[P33] :**

**[P33] ’s** wife [L] developed suicidal thoughts, initially mis-diagnosed as mania. This followed a period of depression and lewd comments to strangers – neither of which were thought of as dementia. Soon after the mis-diagnosis, a psychiatrist proposed assessment for dementia. [L]’s dementia was in its relatively later stages at this point.

**[P51]/[P50]**:

**[P51]** is **[P50]’s** wife and primary carer. **[P50]** has limited mobility, moving between a walking stick and wheelchair. This in particular [P51] feels limits their options for engaging in many activities. [P50]’s journey for assessment began when in contact with a nurse, [P51] responded to speak on [P50]’s behalf, at which point the nurse asked about his communication and memory.

**[P50]** was assessed at Woodlands (psychiatric hospital). Whilst **[P51]** as **[P50]’s** carer was provided with information (referrals to orgs) at that point, this was in the form of literature and referral information and she feels there was a total lack of follow-up assistance.

**[P30] :**

**[P30] ’s** wife **[C]** was assessed relatively quickly, within around 6 weeks. This was pre-covid. As with **[P50]** the MAS took place at Woodlands, who made referrals and the referral organisations made contact with [P30]. The group all commented on how covid appears to have affected services – this seems clearly apparent comparing **[P30]**  and **[P51]’s** experience respectively with Woodlands.

*Memory Advisor/Social Prescriber*

Upon explanation of this potential role, the group were unanimous in the value of this, particularly in relation to the continued role of support post-assessment.

Statements from the group in relation to this role included:

*‘This is where the support needs to be..’*

*‘After the (MAS) assessment you should be called up – change is rapid..’*

This last statement refers to **[P51]’s** experience of seeing her husband **[P50]** deteriorate following the MAS and not feeling prepared or supported for that.

*Referral routes via the social prescriber*

Members of the group were keen advocates of their experiences (via Age UK) of their collective peer support community – leisure activities for both those with dementia and their carers – particularly days out, trips to pubs, dog walking etc.

Without exception, carers within the group experienced their partners’ diagnosis late in their condition(s). As a result, in discussing routes to volunteering, the behaviour of their partners (past and present) presented too much unpredictability when it came to the opportunity for volunteering.

1. **Skills Exchange Service**

*Wellbeing session (skills and interests)*

In relation to wellbeing mentoring, the format rather than the toolkit content was picked up by the group in discussion. [P33] and [P30], each reflecting on their partners’ experiences felt that a group format could provide a more comfortable environment for wellbeing – making the environment more social and supportive. This was evident casually through the session with [P33] and [P30] supporting [P51] and [P50] as newcomers, drawing their attention to local activities and positive personal experiences.

*‘..[C] was better in a group than alone..’ ([P30] )*

*Skills fair*

Picking up on the opportunity for a skills fair, as discussed earlier in the group conversation all carers felt that without early diagnosis skills exchange and volunteering wasn’t a realistic proposition for their partners specifically.

*‘..You have to let people do things in their own time..’ ([P30] ).* This comment referred to **[P30] ’s** and other carers’ experiences with their partners (none of whom received early diagnosis)

*Other insights from the session:*

As across the group, no cases were early onset when diagnosed, the question of how to raise awareness and encourage early diagnosis was explored.

*‘Depression can often be (a sign of) the start..’ ([P33])*

*‘Nobody had knowledge of [L]’s condition (FTD) ...’ [L] would be rude (lewd) to people.. it takes a while to realise the problem..’ ([P33])*

*‘Things start gradually..’* ([P33]) This comment in particular struck a chord with the group

There were shared concerns as to how much currently relies on the effectiveness of the GP (in relation to diagnosis and subsequent referrals and support).

It was felt that GPs and the local authority should promote (dementia friendly) events more.

Covid has clearly had a significant impact on this group and their community, both in the withdrawal of social events and in quality of service provision. To take an example, in the case of Woodlands (psychiatric hospital) **[P30]**  and [**C]’s** experience (pre-covid) offered a more effective and personal referral service than had been the case in **[P51]** and **[P50]’s** experience in recent months – a clear impact of reduced contact

**Group 4: (Isabelle)**

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| --- | --- | --- |
| Pseudo | Gender (male/female) | Role (PWD/carer) |
| [P53] | Male | PWD |
| [P52] | Female | Carer |
| [P24] | Male | PWD |
| [P23] | Female | Carer |
| [P35] | Female | PWD |
| [P34] | Male | Carer |

6 participants – 3 carers and 3 PWD, all at advanced stages – especially [P35](very few interactions with the group). All appeared to be in their sixties/seventies. [P52] and [P23] are very chatty and involved in the conversation, [P34] is more reserved at the beginning. [P35] and [P34] participated in WS 1 with the same moderator, [P24] and [P23] with Kristina. [P53] and [P52] were not there but they are quite new in this dementia café. [P52] works for Age UK Salford, so she mentioned during our discussion it has been easier for her to access information for her husband when needed.

**Dementia journey/service user pathway**

All couples have been referred to a MAS by their GP. For [P24] and [P23], the diagnosis took time as initially, doctors thought it could not be dementia but fluid in the brain (but was mixed dementia – Alzheimer + vascular).

[P24]/[P23] just had their follow-up meeting linked to prescribed medication, etc. – the first one in 2 years. Officially it’s due to Covid but [P23] has the feeling that COVID is the perfect excuse for all dysfunctions/problems now a *“fantastic shield” ([P23]).* They will need to contact their GP again as only this one is allowed to deliver some tablets linked to Sundowning agitation. They regret that it makes it utterly complicated and would prefer having all prescription dementia-related from MAS. Especially because they are not very happy with their GP – he is not very available nor supportive. They also regret the lack of continuity regarding the MAS: they are all the time seeing a different doctor for the memory assessment and have to explain the same story again (including the various scans and professions), *“every time as if it was the first time” ([P23]).* It seems the two other couples experimented more continuity and estimated they have been luckier. For all of them, the first contact has been a nurse that called them following a referral from their GP.

[P23] also mentioned the fact she is uncomfortable with the fact that some sensitive questions and issues were addressed to her in front of her husband, and that it might be quite upsetting for him. [P52] mentioned it has been ok for her because it was asked during a separate time – when her husband was not there.

**Memory advisor/social prescriber**

None of them has been in touch with a *memory advisor*, social prescriber or similar from the GP or MAS – they got all the info and support from [STAFF 1] (Age UK).

They got flyers from the MAS and no real support from their GP – they are mostly in contact with nurses, “doctors stay behind their doors” ([P23]) and appointments are only 10 minutes. [P34] however mentioned his GP said to him to book a double meeting next time (20 min). [P23] highlighted it’s quite a lottery: her sister’s GP did weekly visits when she was very ill from a cancer and even called [P23] to know how she was dealing with the situation. She has been very positively surprised by that. Similarly, support from pharmacists with medication delivery is very different from one place to another. [P23] mentioned that their Boots’s pharmacist was very great – having a chat with [P24] in a separate room regarding the prescribed medications and how to take them – but sadly some medications were not available there – or only after 2 or 3 days.

Participants also mentioned learning a lot from each other during dementia café or other activities – it’s their main source of information (and support). Some carers even have weekly WhatsApp calls to chat and share information and support.

Participants mentioned that more should be done to inform people about dementia, symptoms, medication, taxes, etc. It would facilitate access to diagnosis, services, and support. [P23] mentioned they could have some TV campaigns similar to the ones for strokes so people will have a better recognition of symptoms.

Participants have not been in touch with a *social prescriber* yet but find the concept great and that social activities are important. [P52] mentioned she and her husband very recently joined a chair exercise activity that they had heard about from another carer and they really enjoyed it. It was both a physical and social stimulation – with music and a lot of good cheer. Both of them felt very well in the afternoon after it and [P52] noticed that [P53] was still in a very good mood the day after. This activity has been very fun for him because even if it was difficult for him to follow the exercises, “[P53] liked it because he saw that everyone was happy” ([P52]). [P23] took the occasion to ask her for more information about the timing because she is very interested in trying it too.

Participants did not complain about the situation, praising AgeUk Salford and some other organisations but fully agree that looking for information and support is taking them a lot of time and energy – and is probably not possible for everyone. [P52], that works for AgeUK, highlights that many people are totally lost when contacting them for the first time, usually for a spouse or a parent having dementia symptoms. They usually contact AgeUk when the situation is problematic (and dementia quite advanced).

We then discuss the importance of a positive, strength-based approach to dementia, not only about what is not working fine, “you need to stay positive… we got to do it… we need to give a push for it” ([P52]). We discussed the importance of focusing on what is going well. [P34]might have been not very comfortable with this discussion and left the table at this time to accompany his wife to the toilet. But she is not very communicative, it seems she didn’t ask for it and [P34] made a humorous remark (“walking, she can still do it”) which suggests that the subject was difficult for him and that he preferred to leave the table at that moment. They came back 5 minutes later and [P34] took part in the discussions again.

This is Me and Wellbeing plan

Participants didn’t know these documents but find them useful, for example, to bring with you during medical appointments but also to share with the family “because often they don’t understand because they live far” ([P52], [P23] agrees).

Wellbeing mentor sessions

IT explains the IDoService might offer something similar but linked to activities – which activities/skills are important to me, which skills I could share with other people. They agreed it would be nice. Regarding the individual/group modality, they agree it would be nice to have a document/something to bring home but group sessions with other people would be great too – again they mention it’s their main way to get more info (“because we have to find what is going there”, [P52]). It’s also nice for them to “chat with someone knowing what you’re dealing with” ([P23]) and in consequence a good way to learn more about how to cope with dementia-related difficult situations.

[P52] mentions with a laugh that group activities are really important for them and their wellbeing, but they are usually offered a load of biscuits and tee on this occasion and [P53] cannot repress himself to eat them whereas he has diabetes…

Volunteering and fairs

[P52] highlights that if opportunities to volunteer are offered during fairs, these opportunities should be very local as mobility and travel are very often a challenge. People in Salford will probably not be keen to travel to Manchester.

Again the social and festive aspect was highlighted as something positive, as well as having family-friendly events where children can take part in activities too. Participants mentioned a family day/Olympic game organised by Age UK Salford every summer. [P52] mentioned they are very family oriented so very happy with this kind of initiative.

Related to that, we discussed the fact it was not the case for everyone – and that some people are not very group people – and participants recognised it could be a more complicated situation to offer them activities and support. They suppose these people mainly rely on their GP, MAS, and individual support from organisations such as Age UK.

Goody bag

Participants thought a goody bag would be a nice idea and an efficient way to give information and tips to people with dementia and their families.

They discussed (financial) aids (some of them limited to Salford) that are often not well known or require a lot of bureaucracy/phone calls:

* Taxi vouchers and a related list of taxi firms accepting these vouchers.
* Reduced council taxes
* Blue badge to park (disabled people)
* Carer budget (only Salford?) for the carer - £400 per year for something related to their wellbeing (e.g., gym membership, manicure)
* Carer allowance (for carers that were not retired yet)
* Personal Independence Payment (PIP)

They explained that having all these basic things in one place would be a very good idea because “authorities don’t say about it” but people often have problems with money and pensions.

[P52] agreed that shops and restaurants’ vouchers would be great too. She mentioned some pubs offer discounted early evening meals and it’s a fantastic way to do something different and not stay at home.