

Haringey Future
Services Co-Design
-Dementia and Older
People Day Opportunities-

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EXECUTIVE SUMMARY

This project has been a focused and accelerated piece of co-design involving service users, carers, experts and the Council working together over two months to look at key audience outcomes for the Haringey Community and the different models for service delivery, and then from these developing a series of recommendations around future service commissioning.

To conduct this piece we have engaged with and worked with a cross section of the Haringey Community, Haringey staff, and experts. Whilst it has not been possible to speak to all members of the community we have used a range of methodologies including open interactive workshops, pairs interviews, individual interviews and day centre visits to engage with a broad range of individuals. We have combined the outcomes we heard are important (through these methods) into this document and used these as the basis on which the recommendations are built. These recommendations were then taken back to the community for their input.

It's important to recognise that there is currently significant worry within the community about the proposed changes. The community struggles to see viable alternatives to the current model of service provision and fear a cliff edge when services stop and they are left with nothing.

This report focuses on elderly and individuals with Dementia day services. There are over 850,00 people in the UK living with Dementia and this is predicted to rise to over 2 million by 2051.¹ Each individual's experience is unique and depends on many factors so there is no one size fits all model that works for everyone. For some individuals with advanced dementia and high support needs then day centres do provide a good model, however for others more needs to be done to encourage alternatives.

Key outcomes for service users focus on living a full life and maintain independence. For carers it is about support and help to care for their loved one whilst also living a fulfilling life themselves. When it comes to delivery of services, we have heard that staff are the most important and critical piece. With ensuring the quality, training, permanence and well – being of staff being a key priority for the community.

It's important to recognise that we understand Haringey Council are working towards many of the outcomes and concerns that were heard during this work. However, what is being done is not widely known and therefore more work is

needed on the on going communication and collaboration between the Council and the community.

The key recommendations highlighted in this report are:

- Enable the remaining centres to work as hubs for needs of wider community and look into spinning out of existing centres or have a Social Enterprise on long contract run them
- Work on expanding availability of services out in wider community (breadth and depth) and develop ways for individuals to find out what opportunities are available
- Develop a travel programme to enable access to opportunities
- Provide greater support for individuals with Personal Budgets and help with Personal Assistant recruitment and management

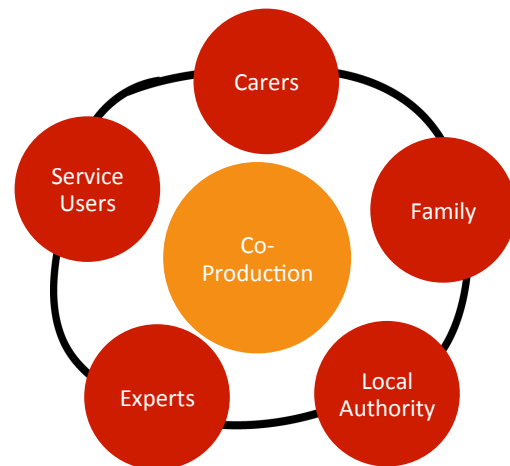
INTRODUCTION AND BACKGROUND

Introducing Co-Design and the scope of this Project

Co-design is a key concept in the development of innovative public services and has been identified as having the potential to make an important contribution to overcoming the big challenges that face social care services.² The Care Act's statutory guidance says that co-design (co-production) is:

'When an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered'.³

This project has approached co-design as the opportunity to get a range of individuals involved in defining the services that will affect them. This has meant service users, carers, experts, and the council working together to create and define the services that they want.



The approach that public services need to be developed in collaboration with the communities that will use the services is not a new idea, however it is one that's benefits have increasingly been recognised.

More recently, the ideas and values of co-design have been included in a growing number of policies in England and Wales including;

- The 2010 NHS White Paper, Equality and excellence: Liberating the NHS⁴
- The 2010 report A vision for adult social care: Capable communities and active citizens⁵
- The 2010 social care White Paper, Caring for our future⁶
- The Health and Social Care Act 2012
- The Care and Support Bill

Haringey Council recognise that the changes being proposed as part of the Consultation will impact on the Haringey community and genuinely want to offer the best possible services and outcomes given the changes taking place. In addition the Care Act 2014 brings responsibilities the council must deliver in:

- Promoting wellbeing
- Preventing reducing or delaying needs
- Information and Advice
- Market shaping and commissioning of adult care and support
- Managing provider failure and other service interruptions

Therefore, Haringey has engaged this piece of work to involve the service users and stakeholders (such as carers, advocates, third sector organisations) in co-creating the answer to some of the challenges that the Council faces.

The intention of this work is that it will help inform future services commissioning regardless of the outcome of the current consultation. As a result this report considers what outcomes are important for the Council, people who use services, their families and their carers.

Following the consultation any changes will be part of a three year programme for the council. It is recommended that throughout this time and ongoing the council work closely with communities to design and create services and opportunities that work for the Haringey community.

This report has been structured simply.

- We have worked closely with service users, family, carers and the community to identify the **key outcomes** for Haringey service users and families.
- We have conducted a market scan to understand services and **service delivery models** that are showing proven success in other areas and boroughs.
- We have looked at **recommendations** for Haringey that combine the key outcomes and proven models

The recommended next steps are:

- Continue the co-design approach and work with service users, carer, advocates, families and other relevant organisation to develop the next level of detail into the new services
- Input these requirements to the commissioning team

This report is part of a series. All reports have been created using the same co-design methodology. Whilst the content and context for each report is different we did find some reoccurring themes and learning's. Recommendations are based on

the specific context of each report, however, where appropriate these recommendations are consistent.

Principles within which this project has worked

Haringey Council has stated an ambition to 'Empower all adults to live healthy long and fulfilling lives', underpinned by the following objectives:

1. A borough where the healthier choice is the easier choice
2. Strong communities where all residents are healthier and live independent fulfilling lives
3. Support will be provided at an earlier stage to residents who have difficulty in maintaining their health and wellbeing
4. Residents assessed as needing formal care and /or health support will receive responsive high quality services
5. All vulnerable adults will be safeguarded from abuse

These objectives are corporate priorities, have a strong whole population Public Health focus but also inform the future operating model for adult social care. The recommendations within this paper fit within these objectives.

Specifically around co-design, this piece of work has followed the principles of co-design identified by Haringey Council:

- Improving outcomes for residents
- Transparency about parameters
- Respect for others' perspectives
- Ability to test ideas and thinking
- Trust and understanding
- Space to acknowledge the challenge of working differently
- Advocacy for users
- Willingness to think through ideas and change our minds, within the parameters
- Steadfast adherence to the values and principles of Corporate Plan – e.g. building capacity and resilience, prevention and early intervention, promoting independence, fairness and equity, partnership working, value for money, customer focused.

PROJECT DETAILS

The key objective from this piece of work was to identify and co-design new approaches to the provision of Elderly and Dementia Day Opportunities. In order to achieve this there are a number of sub-objectives:

- Ensure service users are involved and engaged
- Understand the key outcomes and motivations of the service users and their carers
- Identify a range of delivery options that realise these outcomes

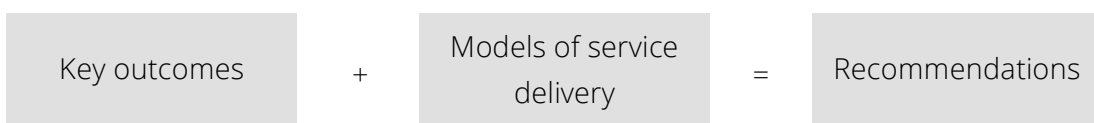
To deliver on the above objectives this project has been approached in three stages.

Stage 1: Market Scan - Create a baseline of potential service delivery models through interviews with experts Interviews, desk research and staff workshops.

Stage 2: Audience Insight - Get a deep understanding of the audience's outcomes and reactions through open community workshops, paired depth interviews and telephone depth interviews with service users and carers.

Stage 3: Co-creation - Work with audiences to understand the pros and cons of the different options and then write up the recommendations through community workshops.

This report is structured as a write up with the following structure:



We conducted initial research to provide the community with examples of models and outcomes, received feedback on these and identified others. Then conducted additional research to support the findings.

About Good Innovation

At Good Innovation, we want to solve the problems that matter. We do this by helping organisations doing good to grow their impact. Our philosophy is about designing products and services that are based on users' insight and involvement in the development process. We have worked with lots of organisations (including, Reed in Partnership, Mind, Save the Children, RSPCA, NSPCC and Diabetes UK) to

develop products and services that ultimately help them to increase their impact.

Who has been involved in this project

As part of this process we have spoken with a wide range of community members to gather their input and understand their outcomes. We have focused especially on Service Users from the Haynes, the Grange and the Haven. Whilst it has not been possible to speak to everyone we have attempted to speak to a cross-section of the community through a variety of methods. We understand that the council's intention is to append this work to the outcome of the consultation. It has been our role to listen to and facilitate the community to share their outcomes as an impartial party.

Community	Number
Service Users	6
Carers	18
Other Stakeholders	7
Experts	12
Total	43
This work has also been informed by the LDX advocacy piece.	

KEY OUTCOMES FOR COUNCIL

The first part of this project focused on identifying the most important outcomes for the council, service users and families. From a council perspective the outcomes that are important are below, these have been highlighted as part of the 2015 / 2016 corporate plan.

(http://www.haringey.gov.uk/sites/haringeygovuk/files/corporate_plan_2015-18.pdf)

Prevention and Early Intervention – Identify individuals more likely to need support and delivering that support earlier. Also important is delivering and going above the duty of care to ensure adults within Haringey are **safeguarded**.

A Fair and Equal Borough - Working to develop healthy and sustainable communities so residents can live happy, successful, fulfilling lives. Ensuring **inclusion** and enabling all individuals to feel part of the Haringey community.

Working Together with Our Communities - Building resilient communities where people are able to help themselves and support each other through facilitating, enabling and connecting communities with resources, skills and capacity to make things happen. This includes taking a **co-design** approach where possible to design opportunities in collaboration with the community. In addition this includes better **signposting of local resources** and **connecting skills and willingness** with where it can really make a difference

Value For Money - Achieving the best outcome from the investment made by measuring cost and performance, and identifying efficiencies.

Customer Focus – Focusing on the needs and outcomes that are important to the Haringey community and delivering on these. Promoting a **breadth of opportunities** for example, day centres, help and advice and intensive interventions, that meet these different needs and outcomes. Enabling Haringey residents to live **independent** and fulfilling lives by giving individuals more choice and control but with support according to needs and aspirations.

Working In Partnership – Working with partners and partnership boards across the borough to agree a common set of principles around shared working and jointly set targets and milestones.

KEY OUTCOMES FOR SERVICE USERS

From a service user perspective the following outcomes highlight what they need help with to live full and fulfilling lives. This section is structured as:

- The outcome that we heard is important to the service users and their carers
- Assessment of how well the current service provision meets these outcomes
- A case study of this outcome being met well. This is not meant as a recommendation, it's meant as an example of how different people are addressing the topic
- How this differs / links to Council outcomes
- Recommendation

"I enjoy spending time with my friends, it is important for me to have my own life"

For individuals with Dementia it can be hard to establish and maintain meaningful relationships so having people they spend time with regularly helps them to establish friendships and enables them to have their own space away from carers.

- For mum in a lot of interactions her memory gets in the way but here [at Haynes] she is one of the best. (Carer Dementia)
- My husband likes to socialise but not with new people. It needs to be familiar faces. (Carer Dementia)
- The day centre is her only real chance to see other people. (Carer Dementia)
- I would like it if someone would do befriending for my husband, as he doesn't like to leave the house. We tried it once but he didn't like the person. (Carer Elderly)

For individuals attending day centres they meet this outcome. However, for those with less severe needs or that don't attend the day centre it can be difficult to maintain existing relationships and develop new relationships. Their social circle often shrinks to just carers and close family.

Whilst there are some social opportunities run by organisations such as AgeUK one of the challenges is that transport can be difficult.

This is an outcome where what the council wants seems to be consistent with what services users want. For the council to deliver on their outcome of developing healthy and sustainable communities so residents can live happy, successful,

fulfilling lives enabling social circles and relationships is essential.

Recommendation: We recommend booting the number of opportunities for individuals at different stages of Dementia to meet and maintain friendships. This should be co-designed with the community but as an indication is should include activities such as:

- Social Clubs
- Shared Interest Groups

GoodGym (www.goodgym.org)

A company limited by guarantee developed from Social Innovation Camp 2008. The GoodGym is a community where its members run whilst also doing good.

Members will combine a group or individual run with one of three things:

- Manual labour for community organisations,
- Make social visits to isolated older people
- Help vulnerable people by doing odd jobs

By having the opportunity to meet and develop relationships with individuals in their community the runners also help to extend the social circles of isolated older people.

The GoodGym operate in Brent, Bristol, Camden, Hackney, Islington, Lambeth, Newham, Tower Hamlets and just launched in Haringey .

“I want activities that keep my mind stimulated. I get bored staying home all the time.”

Dementia limits individuals lives, the activities they previously had confidence to do often are given up and peoples lives contract. As a result individuals find themselves confined to their homes feeling bored and like they are being baby sat

- I like to go out, it passes the day away. Otherwise it is boring. (Service User Dementia)
- I don't like wasting time with TV. It feels like I am not learning anything. (Service User Dementia)
- She really likes to go out everyday for a walk, she gets to see people. The walk is really important. (Carer Dementia)
- I like it when I get the chance to be creative (Service User Dementia)

This again is an important role that Day Centres play for the people who are accessing them. They give individuals a sense of purpose and reason to get up in the morning. However, for individuals with less severe needs the day centres can seem to just 'waste' the day with pointless activities. They want more of a range of activities and the opportunity to carry on doing the things that they have always enjoyed.

Again this seems to be an outcome where the council and service users are in agreement.

Recommendation: Increase the opportunity for purposeful or interest led activities outside of the day centre for the elderly and individuals with Dementia. These could include both small and large group settings.

Mens Sheds (<http://menssheds.org.uk/>)

A Men's Shed is a place where men get together and pursue practical interests. In a Men's Shed members share the tools and resources they need to work on projects of their own choosing including local community projects.

Mens Sheds provide older men and those with mild dementia with a space to meet and socialise with others, the opportunity to do practical and skilled activities and the ability to have an impact in their community.

Every Bloke Needs A Shed was a two-year pilot program run between September 2011-2013 by Alzheimer's Australia NSW, in conjunction with the Australian Men's Shed Association, which encouraged and supported both men with early stage dementia or a mild cognitive impairment, and male carers, to access and participate in the activities available in their local Men's Shed.

“I need help to know what is out there for me to do”

For individuals and carers, knowing what activities and services are available to them is difficult. There is no one place to go for information so often the day centre acts a hub for advice and info.

- We used to have lots of things we did like Age UK at St Anns library but everything stopped. (Carer Elderly)
- I go to the library and look at the notice board to find out what is available. (Carer Dementia)
- I would like more options at different times, like evenings and weekends. (Carer Dementia)
- More information would be good. For me as well. (Carer Dementia)

For those that use them, the Day Centres are the primary point for providing information about the opportunities that are available. They operate as informal hubs of information for service users and carers.

Outside of this, there is a large gap in terms of information on what is out there for individuals. Service users and carers mentioned they mainly found out about different activities and opportunities through word of mouth (from other users, carers and council staff). One of the biggest frustrations is that there isn't an easily accessible source of information.

This gap seems to be something that the council has also committed to tackling through their outcome of enabling greater communication and sign posting of community resources.

Recommendation: This is a gap that all parties have identified. We recommend that the council and the community work together to identify and develop ways to make information around the availability of opportunities in the community and the appropriateness of these for individuals easily accessible and available.

Local Area Coordination

inclusiveneighbourhoods.co.uk

Local Area Coordination is the development of 'coordinators' based in a locality who act as a single, accessible, point of contact for people in their local community, irrespective of their age or service label. They work with individuals to understand their gifts, skills and contributions and then help them to find and use these to achieve their outcomes and live fulfilling lives. They are based in the community at a location the community chooses (the community also helps to recruit Local Area Coordinators) and can provide support in several ways:

1. Understand and nurture their gifts, skills, experiences and needs
2. Access accurate, relevant and timely information
3. Build a positive vision and plan for the future
4. Build and maintain valued, mutually supportive relationships
5. Be part of, and actively contribute to, community life
6. Help people be heard - encouraging self advocacy, advocating alongside people, or advocating for people if there are no other options
7. Find practical, non-service solutions to issues and problems wherever possible
8. Access, navigate and control supports and services, if these are required

Currently operating in Derby City, Thurrock, Suffolk, Isle of White and other areas it has shown to be extremely valuable resource to the community.

"The Local Area Coordinator is genuinely interested in me and does not have an agenda. I feel completely in control and that the Local Area Coordinator is on my side. There are things that I have done that I wouldn't have been able to do without the support of the Local Area Coordinator."

“I need help getting to places. Without transport or someone to go with me I am stuck”

Both carers and individuals talked about the importance of transport to enable people to get out and access activities. It is not enough for activities to exist – without appropriate transport and support people are not able to access these

- “Better transportation would be really good. It would make it easier to get out and about.” (Carer Dementia)
- “Someone to help us get out and about would be the biggest help.” (Carer Dementia)
- “The effort to get anywhere often outweighs the benefit.” (Carer Dementia)
- “If I get a taxi I need to get her down the stairs myself and lift the wheelchair. The good thing about Haven is that they pick up from indoors.” (Carer Dementia)

Currently transport is an issue for many service users in Haringey, unless a service has travel arrangements many individuals feel unable to access the service.

The council has also identified the importance of developing travel options.

Drivers for Change - Northumberland

Northumberland County is working with local bus training providers to develop a Dementia awareness training package for all its bus drivers.

The training focus' on awareness and practical measures to support passengers. This has been developed in conjunction with people with different needs and stages of dementia and their families.

Recommendation: That a travel arrangement approach that encompasses a greater number of options and solutions for individuals, as well as support to use these, is developed.

“I want staff that feel like they are family”

Staff are the most important factor for both individuals with Dementia and their carers. Having consistent staff, who care as much as a family member about someone's wellbeing is important

- “The staff here are really good. They notice the small things. That’s important with Dementia.” (Carer Dementia)
- “How good the service is depends on the people. Some are great. Some are terrible.” (Service User Dementia)
- “It is important for her to see familiar faces. With Dementia being able to recognise people is so important.” (Carer Dementia)
- “I am a bit tainted by the extra care staff. They are nice but there isn’t the same dedication.” (Carer Dementia)

Currently the staff at the day centres feel like friends and members of the family for the service users that attend the centre. The thought of losing those staff is one of the largest concerns for services users and carers. Outside the day centre service users and carers talk about the importance and difficulty in finding and hiring support workers that they trust

Haringey has identified up skilling and training their staff as an important outcome and recognise they need to work with providers to do the same.

Recommendation: Future service commissioning prioritises experienced, trained staff are an important factor in any future delivery model.

The Dementia Centre – Nazareth House Care Village Training

The Dementia Centre delivered low cost Dementia training to members of staff at Nazareth House Care.

It was delivered at the Nazareth Village it self allowing:

- staff to be freed up from their work,
- costs to be kept as low as possible
- everyone to relate the learning directly to where they worked.

Has had a significant impact “the training has quite simply transformed the way we think and work at Nazareth House. We have already scheduled more training so all our staff get the full value of what the DSDC offer” Siobhan Regan, Manager Nazareth Care

I want to stay fit and healthy, otherwise I'll just seize up

Staying active is important as individuals age and whilst a lot of exercises are not appropriate or possible walking is something that becomes of increasing important. A way to get about, to retain independence and to stay well.

- I want to feel as good as I can for as long as possible.
- Service User Dementia
- Getting his feet done is really important to help him stay active.
- Carer Dementia
- I like to dance it helps me feel young.
- Service User Dementia
- Walking is really important. It keeps him fit and healthy and gives him a bit of freedom. He goes on his own sometimes.
- Carer Dementia

Some low impact physical activity sessions are part of the activities at the day centres. However, service users and carers talked about the importance of going for walks and seeing the world and coming across other individuals, Currently the only opportunity for individuals to do this is if they go on their own or with a carer.

The Walking Group – Forget-me-not Centre Swindon
www.innovationsindementia.org.uk/videos_walkinggroup.htm

A walking group for individuals and their supporters that goes on local walks in the area around the Forget-me-not Centre. Gives individuals the opportunity to do an activity they enjoy, keeps them healthy and also build relationships.

The council's outcome of developing healthy and sustainable communities demonstrates that this is an outcome that is important from a council perspective also.

Walking Football (various)

Walking Football is a slow-paced, non-contact version of the game aimed at the over 50s, designed to tackle both inactivity and social isolation. It is perfect to get those back playing football who perhaps stopped due to injuries. There are a large number of activities for older people, however the majority such as tea-dances or Pilates tend to be dominated by women, Walking Football is an excellent alternative for older men.

Recommendation: Opportunities that provide physical activity outside of the day centre for service users who are able to participate are encouraged.

“I want to maintain my independence and be able to do things for myself”

Maintaining independence and enabling individuals with Dementia to have autonomy, both in their actions and choices is important to make sure we are not restricting peoples freedom

- I want help to do things for myself. Not have someone do it for me. (Service user Dementia)
- I hate it when people make too much of a fuss over me. I would rather they let me do things and then check I am ok. (Service User Dementia)
- I want to feel independent and getting out of the house helps me do that. (Service User Dementia)
- He likes to go for walks by himself. He knows where he is going and knows people nearby. It makes him feel free. (Carer Dementia)

Maintaining independence is a huge priority for individuals diagnosed with Dementia. Being able to adapt their lives and developing coping strategies for doing things on their own is something they say is key.

Service users and carers identify this as an area where more can be done to help the elderly and those with Dementia to maintain their independence for as long as possible.

Prevention and early intervention is one of the key outcomes identified by Haringey council. So the community and the council both agree this is an important area to focus.

Recommendation: Further development of services and opportunities that focus on prevention and enabling individuals to stay well.

Intensive Support Teams (Various)

Intensive Support Teams provide short term support to enable older people with dementia to remain in their own homes and to support hospital discharge. Key features of this intervention include:

- helping people ‘to do’ rather than ‘doing for’ them
- supporting people at a time of crisis
- outcome focused support from care workers with defined maximum duration
- subsequent ongoing care packages not defined by a one-off assessment but through observation over a reasonable period (typically around 6 weeks)

KEY OUTCOMES FOR CARERS

“I need activities that take up time and give me a break to do other things like go to the shops and have a rest”

Caring for an individual with Dementia is a 24 hour job without a day off. As a result carers can feel overwhelmed. Having a break for a few days a week or respite every now and then is important in helping them cope.

- “If I didn’t have the day centre then I would have to give up work and look after mum”. (Carer dementia)
- “ The centre gives me a break and lets me live my life”. (Carer Dementia)
- “Our family is nearby but if you are the main carer there is lots of things you need to do so it is really hard. It is constant so having a break helps.” (Carer Elderly)
- “If mum wasn’t here I couldn’t work full time”. (Carer dementia)

For carers whose loved ones attend a day centre this is one of the most critical roles the Day Centre plays. For other families they have spoken about support workers and respite as being a key way to cope.

One of the big worries that emerged was around the availability of opportunities that could provide respite if the day centres go. People didn’t feel that the opportunities currently available in the community outside the day centre provide this.

Admiral Nurses (various)

Admiral Nurses are specialist dementia nurses who support the whole family providing both high level emotional and practical support to enable them to deal with the complexities they face living with the effects of dementia. An evaluation of a two-year pilot in Norfolk showed that Admiral nurses improved carers’ mental health and increased their “ability to carry on”. In addition, 94% of health and social care professionals surveyed said contact with the Admiral nurse service had increased their confidence in dealing with dementia patients and their carers.

This outcome is also important for the council considering it’s focus on working with communities and building resilience.

Recommendation: Ensure there are enough opportunities available that are of a longer duration to provide carers with the opportunity for respite.

“I want to meet other people in the same position who understand what I am going through”

Caring for someone with Dementia can be extremely isolating. Having the opportunity to meet others and share experiences and advice is important to enable carers to stay well and cope with the pressure of looking after someone.

- “Haynes give me help and advice also.” (Carer Dementia)
- “I used to go to carers meeting. It is self help and chance to talk to others and tell each other about activities.” (Carer Dementia)
- “For me meeting other people helps break the monotony of being a carer all the time.” (Carer Dementia)
- “For me meeting other people helps break the monotony of being a carer all the time.” (Carer Dementia)

For carers whose loved ones attend a day centre there are carers support groups that play a key part in providing support, advice and friendship to carers.

For those carers whose loved ones don't attend the day centre the support is more patchy. We heard about other support groups that operate, some run by Alzheimer's Society but found that carers are still isolated and can feel alone.

Toms Club Haringey

Toms Club is a service for individuals with Dementia and their carers. The club provides joint respite for dementia sufferers and carers who attend together. It also gives carers a chance to meet other carers and avoid isolation. It is a source of info and advice for carers as well as an opportunity to meet others.

This is also a shared outcome for the council.

Recommendation: Further development of support services and information and advice for carers.

KEY CONSIDERATIONS

As a result of the current environment and the nature of the audiences impacted there are some considerations to be aware of that impact on this project.

Need for change - the Haringey community questions the need for change. Whilst the growing budget pressures and increasing demand are a reality the community is aware of, they question whether the cost savings should come from cutting 'essential services' as opposed to reducing administrative budgets and finding efficiencies elsewhere within the local authority. This feeling that "Haringey should get its finances in order" means that many members of the community feel reluctant to engage with looking at alternative service models.

On-going budget reductions - another factor is that all the changes that have happened over the past few years to services have understandably had an impact on the community. They feel that it is "cuts cuts cuts" and "all they care about is the money". This is another factor that means the community questions whether to be involved in this type of work, "what is the point if they're just doing it for money. They'll just go with the cheapest option." In addition the community feels that by being involved they are condoning the cuts that they oppose.

The implication of these two points is that Haringey Council need to do further work on communicating with the community around the changes. This does not imply that more meetings are needed, and in fact we heard 'there is so much consulting of us and nothing getting done'. But instead looking at alternative ways to engage and involve the community in the process is important. This won't be a quick fix; continuing with the co-design approach can be a way to help facilitate some of this change.

Protective of services they use - When speaking to individual service users and their families, they are understandably protective of the changes that impact them. As this is a sensitive time with a lot of change being proposed, it can be difficult for individuals to engage in design work that goes beyond the impact on them.

The implication for this is that Haringey Council's communications and engagement should be clear and focused on the specific impact of the changes on people, particularly focused on providing reassurance around some of the major worries. We noticed that there were lots of assumptions about worst case scenarios (such as people being forced into a 'home' and 'abandoned'). It's natural that the challenging

nature of the situation around such an emotive topic will have people fearing a worst case scenario. The Council should continue to work hard to address these worries and reassure people.

Given the challenges highlighted we recommend that the community and Council continue to build on this project by working together. Whilst we acknowledge that this is difficult given the history and tension there needs to be trust that the Council want to make the best decisions for individuals' care as possible and this can only be done in partnership with the community. We encountered signs that this is possible through this co-design process as we saw some people recognise the value of this piece of work and how it can help them influence future commissioning.

Dementia considerations – There are over 850,000 people in the UK living with Dementia and this is predicted to rise to over 2 million by 2051.⁷ Currently Dementia costs the UK £26.3bn per year and by 2026 this cost will have risen to £35 bn. The current and future impact of Dementia is a significant challenge that means a greater number of services and support are required in future to help individuals impacted by Dementia.

Dementia impacts on all aspects of a person's life, and each individual's experience of Dementia is unique and depends on many factors, so it is important to note that there is no one size fits all model of services. Ensuring a breadth of opportunities across different stages of Dementia is key.

For service users with Dementia the impact of changes on well-being are generally greater than for individuals without Dementia. As a result it is important to understand and consider the impact that changes will have on Haringey individuals.

Desired outcomes – We have observed that many of the community's and councils' desired outcomes are consistent. This is positive and suggests that further collaborative co-design work will be beneficial. The ambition is for this piece of co-design work to be the start of a on-going co-design approach at Haringey Council.

MODELS OF SUPPORT

Working with service users, carers, experts and staff we looked at different ways that services can be delivered and explored some of the advantages and worries that arose.

Activities at a Day Centre provided by council staff

This model was the preferred model of the audiences we spoke to. It's the current model so it the most familiar, and the model most people wanted to remain available.

Advantages	Questions
<ul style="list-style-type: none"> • Staff are permanent, dedicated, well paid • Council are required to care and provide support • Good for meeting people and socialising • Level of consistency and monitoring in delivery • Secure and routine for user • Place to go for advice • More peace of mind as council is accountable. 	<ul style="list-style-type: none"> • Forces different needs and abilities together 'warehousing' • Individuals are separated from the community • Don't take risks / lack of development of services • Lots of bureaucracy to make changes • Not so many available now • Transport and access not always easy • Catering for ethnic minorities?

Activities provided by a charity or social enterprise on their premises

This model was mixed in the mind of the audience. Some charities / social enterprises were trusted in their ability to offer good services but the audiences questioned the ability of charities/social enterprises to offer the standard and equivalent of the council Dementia day services . The biggest worry was the sustainability of the charity or social enterprise and how they could balance delivering a quality of service with their cost base.

Advantages	Questions

<ul style="list-style-type: none"> • Run by passionate people • Encourages social enterprises to improve • More flexible • Social enterprises will have good specialist and trained staff • Provide a holistic service (families and carers) • Important how run, not who runs 	<ul style="list-style-type: none"> • Is it value for money and affordable? • Staff on zero hours contracts and short term contracts? • Admin and bureaucracy for families to manage payment • How well service is run and monitored • Suitability of the space • Availability and permanence of service (Age UK service in Haringey declining)
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Activities provided by community volunteers on other premises (e.g. community centre)

The idea of this model was welcomed as a supplement to existing services. Whilst people could see the value of this as a way for some service providers to increase their staff it was felt that this wasn't viable for the entire provision of a service as it would be too unreliable. Another issue was transport and the ability of individuals to get to and from activities

Advantages	Questions
<ul style="list-style-type: none"> • Motivation of people who manage the activity • Means more of a breadth of different activities for different interests • Good if used in addition to other services • Involves people who are passionate about subject • Diversity and ethnic groups 	<ul style="list-style-type: none"> • Skill and competency of volunteers • Training, supervision and management of volunteers • Not permanent • Current, up to date info on what is out there • Who's paying for the cost of things such as room hire?

Activities provided via Skype (or other telephone / video call service)

This model was seen as having a role but only in specific situations and for certain types of service user.

Advantages	Questions
<ul style="list-style-type: none"> • Keeping in touch with people • Reducing social isolation • Quick advice phone lines • Regular contact for people who can't get out 	<ul style="list-style-type: none"> • Ability to use and maintain technology • Not appropriate for all • Not for professionals giving advice

Activities provided by friends and family in my home or in my community

Again, this model was seen as having a role but also something that is already happening in the community. This model was actually what some people feared that the cuts would do as they felt they would be unable to cope.

Advantages	Questions
<ul style="list-style-type: none"> • Good neighbour schemes • Community interaction 	<ul style="list-style-type: none"> • Happens already • Not good if all activities done this way • Might not have friends or family • Safeguarding

Activities provided by a Personal Assistant in my home or community

This model was welcomed in theory but there were a lot of questions / concerns about how this would work in practice. People had often heard about the idea of Personal Assistants and also some of the issues that came with this – such as the admin, paying for holidays, pension requirements etc. If this model is to be used then work will need to be carried out to support people to understand these areas.

Advantages	Questions
<ul style="list-style-type: none"> • Support to do things that are wider than just 'care' • Individual personalised one to one care • Might have specialist skills like speech therapy (dementia navigators Islington) • When it works out the PA is also a friend / companion 	<ul style="list-style-type: none"> • Dependent on PA, their skills, motivation, personality and finding the right person • Supervision of PA • Relative cost of PA compared to a centre • Hassle and worries about managing PAs (pension, maternity leave, holidays etc)

Activities provided by peers and other service users in my community

Again, this service delivery model was welcomed by many on the basis that it would supplement other 'core' activities rather than entirely replace them.

Advantages	Questions
<ul style="list-style-type: none"> • Personal shared experience (expert patient schemes) • First hand experience • Things in common (mentoring / silver surfers) 	<ul style="list-style-type: none"> • As per volunteers

Conclusion

There are advantages and disadvantages to each model, however, what is clear is that there is no one size fits all solution for the breadth of needs and individuals within the Haringey community. As a result it is clear that a variety of service models are necessary to meet the breadth and depth of needs in the community (as also highlighted as part of the Care Act).

Reviewing the models in this way enabled us to identify some key elements that are important in the delivery of any opportunities:

Vetting and quality monitoring - the council run services provide peace of mind as the community believes they are held to a higher standard than externally run services. In addition, the community feels there is greater accountability for these services, if something goes wrong you know where to go and complain and you know someone has to do something about it. Therefore, in enabling external running of services the council should develop requirements for vetting and on-going monitoring of services in partnership with providers.

Staff are the most important factor - When it comes to the biggest concerns about services or opportunities that are not council run, staff are the most important factor. The community worries about staff that are not employed by the council resulting in:

- Inconsistency and high turn over
- Zero-hours contracts
- Low pay and bad staff conditions
- Lack of training and specialisms

As a result any commissioning of external services needs to work closely with the community and providers to ensure that these concerns are met.

High costs of external providers - another big issue of alternative models for the community is the worry that they will be able to afford less support. They worry if they are allocated a personal budget and the cost of external providers is higher than the council cost then the amount of support they are able to receive reduces. To ensure this does not occur the council should work closely in commissioning services to ensure the cost to the community is affordable.

Range of individuals with different needs - another key point is that whilst there are advantages and disadvantages to each model, there is no one size fits all solutions for the breadth of needs and individuals within the Haringey community. As a result it is clear that a variety of service delivery models and opportunities are necessary to meet the breadth and depth of needs in the community. This is also a requirement of the Care Act. The council should work with the community to develop enough of a breadth of different activities and services supporting individuals at different levels of need, and that enable individuals to find out about these.

Management and recruitment of PAs – a further issue highlighted was the worry individuals have about the management and recruitment of support workers. They worry about being able to find the right person and managing their employment. The community needs greater support in finding personal support workers they are happy with and managing them on an ongoing basis.

RECOMMENDATIONS

Overall principles identified as important:

As part of this piece we worked with the community to identify nine high level requirements that future service delivery should deliver. Haringey Council has agreed to adopt these.

1. Quality monitoring of all activities and services in Haringey
2. Accessible and up to date information about activities and services
3. Mobilising community volunteering and supporting this with infrastructure and quality monitoring
4. Working with providers so staff are well paid and have good working conditions
5. Working with providers to encourage staff development through training and development of specialist skills
6. User, partners and staff involvement in the development and delivery of opportunities
7. Enabling service users to live a fulfilling life
8. Working with the market to develop a breadth of services and activities to promote choice, from long term preventative aims to end of life care
9. Developing availability of sustainable opportunities

Proposed Recommendations

The outcome of this piece of work is that we recommend Haringey Council look at the following.

Work on expanding availability of services out in wider community (breadth and depth)

The community has identified that more needs to be done to develop and create a wider range of opportunities for individuals and also enable individuals to have greater choice in finding things that interest them.

One of the key roles for the council needs to be working with the community in order to foster and develop a greater number and breadth of different types of services.

Community Catalysts
communitycatalysts.co.uk

Community Catalysts is a Social Enterprise that works with Local Authorities to nurture very small (micro) community enterprises, groups and initiatives that care for or support people in their local area and offer them real choice

As an example, 'Helping to Remember' is a community micro-enterprise for people living with a memory impairment or the early onset of dementia in West Somerset. John Baly, set up the service following 14 years of being a full time carer for a relative living with dementia. 'Helping to Remember' focuses its support on more active people, who may have lost confidence or experience frustration and isolation. This can mean anything from going on walks, playing scrabble and pub lunches to shopping trips, medical appointments and visiting the barbers for a haircut or shave. John works in co-operation with families to focus on strengths and reconnecting with what people can do.

Develop a method for individuals to find out about what services are available

One of the biggest issues that individuals have in the Community is access to information on what services and activities are available to them in their community. Individuals said they usual find out about different services or activities through word of mouth or searching extensively.

As a result one of the biggest service gaps currently is the ability to know what is out there for individuals to access.

One way that Haringey is currently delivering support in this area is through the Neighbourhood Connects Project. Neighbourhoods Connect works by people sharing their skills, interests and time with others. The project supports people to make new friends, connect to social activities, hobbies, fitness and well-being services, community groups, volunteering and befriending opportunities in Haringey.

The Council should do further work with the community to understand how else to share information around opportunities and also provide more support to individuals.

Local Area Coordination - Derby
communitycatalysts.co.uk

Local Area Coordination is the development of 'coordinators' based in a locality who act as a single, accessible, point of contact for people in their local community, irrespective of their age or service label. They are based in the community at a location the community chooses (the community also helps to recruit Local Area Coordinators) and can provide support in several ways such as understanding and nurturing their gifts, skills, experiences and needs, accessing information, helping people be heard (advocacy) and more (please see page 17 for details)

Local area coordination began in Derby three years ago as an attempt to understand how the council could meaningfully support citizens to build on, build up or even establish for the first time their own social capital, based on relationships and connections with family, neighbourhood and the wider community.

"Ben has been great, he has coordinated everything and got things moving where they weren't before."

Develop a travel programme to enable access to opportunities

Another major issue raised by the community is access to activities and services. Regardless of if a person has had the cost of transportation included in their Personal Budget Needs Assessment, it is often hard for individuals to access services that don't have transport associated with them.

This issue is two fold:

1. Availability of suitable transport
2. Support to access this transport

Whilst the area has great public transport it can be difficult for individuals with Dementia or mobility issues to access this.

The Government also has a document on the benefits of Travel Training (Travel Training: Good Practice Guidance, 2011)

Drivers for Change: dementia-friendly bus transport in Northumberland

Northumberland is developing a dementia awareness training package for local bus drivers for inclusion. The county has established the Northumberland Dementia Forums which draw together people with dementia, their carers and voluntary organisations. These groups raised difficulties about using local buses, especially for people in rural areas once the individual or their carer had to give up driving. Family concerns about the safety of and support available to their loved ones when out in the community were among the wider issues also identified. The training development stage identified that a more sustainable and effective process is to work in partnership with the existing providers of driver training to develop an enhanced package that focuses on awareness and practical measures to support passengers. This is informed by people with different needs and stages of dementia and their families across the county through the forums

Look at helping with Personal Assistant recruitment and management

Individuals and their families have all spoken about the importance of the people providing support. Often it is the personality and dedication of individuals that mean the difference between adequate and great care. Individuals within the Haringey Community have identified a gap with support for finding

Equal Lives
www.equallives.org.uk/

Equal Lives is a user led organisation set up in 1996. They provide a number of services including advocacy, advice and helping individuals to find and recruit a personal assistant.

and managing their support workers.

Enable remaining centres to work as hubs for needs of wider community

Individuals have said that the Day Centres often act as information and support hubs in addition to providing day services to individuals. As a result encouraging the centres to 'open up' their doors and enabling other clubs, activities and services to use the premises could be a way of making these act like a 'hub' for the needs of the wider community.

Toms Club Haringey

Toms Club provides joint respite for dementia sufferers and carers who attend together. It also gives carers a chance to meet other carers and avoid isolation. It meets at the Haynes Centre and is open and welcoming to all individuals with Dementia and their carers.

Look into spinning out of existing centres or having a Social Enterprise on long contract to run them

We heard during the interviews that some carers and staff members were interested in finding out more about separating out existing services from the council. Since 2010 the government has been encouraging council and government staff to take responsibility for the public services they deliver, spinning them out into independent, employee-led mutuals and leaving the public sector. This model gives staff and service users greater control over the running of the service and enables it to operate automatically from the council.

Leading Lives, Suffolk (leadinglives.org.uk)

Leading Lives spun out of Suffolk Council as an independent mutual in 2012. It provides supported living, community support, short breaks, hubs, day opportunities and more. It has not closed any services and now offers more support for domiciliary care and personal budget management.

Just 20 months in, Leading Lives now employs 500 staff, 70% of whom are members of the mutual.

Greater Support For Individuals With Personal Budgets

It was clear from conversations with individuals and community forums that Personal Budgets is another area the community wants support with. With the

majority of service users moving or on Personal Budgets within the borough more needs to be done to support the community with training and support for on going management. This should be through enabling forums for discussion and support (there is already a very popular forum within Haringey), help and advice on how to spend their budget and for when things go wrong, and access to advocates for ensuring the community feel they are getting the right support.

Another area is enabling individuals money to go further, one way that this can be achieved is to enable Individual Service Funds (ISF). These act as a 3-way arrangement between a local authority, the person and a provider organisation who act as a broker. The broker is a paid worker whose role is to support the person and their family to work out how best to use the budget so that they get best value out of it.

Richmond Users Independent Living Scheme (ruils.co.uk)

RUILS is a user-run and led organisation providing adult social care services in Richmond, London. RUILS helps individuals across a broad range of areas including employing a Personal Assistant through to pooling personal budgets collectively with others. RUILS is a local, user-led charity supporting individuals (irrespective of age, impairment, health condition or capacity) to live independently at home and in their community.

GOING FORWARDS

In order to take this work forwards we recommend the following next steps:

- Taking each of these recommendations to implementation stage
- Forming a co-design project team of service users, carers, advocates and staff that will work together with commissioners.
- Further defining the detail of the recommendations that are taken forward to develop a more detailed set of requirements. Work out aspects such as:
 - A more detailed market mapping to understand the current infrastructure in Haringey in more depth
 - Further exploration of examples where solutions have worked elsewhere to understand the learnings
 - The cost and financial model
 - The operating model including how it works within Haringey
 - The experience of how it works for the service user
- Following this, involve the co-design team in the commissioning process.

GLOSSARY:⁸

Assessment	The process of working out what your needs are. A community care assessment looks at how you are managing everyday activities such as looking after yourself, household tasks and getting out and about. You are entitled to an assessment if you have social care needs, and your views are central to this process.
Assets	Things you have that may be valuable in money terms (such as a house), or useful in other ways (such as particular skills, knowledge or relationships).
Carer	A person who provides unpaid support to a partner, family member, friend or neighbour who is ill, struggling or disabled and could not manage without this help. This is distinct from a care worker, who is paid to support people.
Co-design	When you are involved in designing and planning services, based on your experiences and ideas. You may be invited to work with professionals to design how a new service could work, or to share your experiences in order to help a service improve.
Commissioner	A person or organisation that plans the services that are needed by the people who live in the area the organisation covers, and ensures that services are available. Sometimes the commissioner will pay for services, but not always. Your local council is the commissioner for adult social care. NHS care is commissioned separately by local clinical commissioning groups. In many areas health and social care commissioners' work together to make sure that the right services are in place for the local population.
Joint Strategic needs assessment	The process of identifying the future health, care and <i>wellbeing</i> needs of the population in a particular area, and planning services to help meet those needs. This process is led by your council, working with the NHS and private and voluntary organisations in your area.
Outcomes	In social care, an 'outcome' refers to an aim or objective you would like to achieve or need to happen - for example, continuing to live in your own home, or being able to go out and about. You should be able to say which outcomes are the most important to you, and receive support to achieve them.
Outputs	The things that an individual or organisation produces as a result of the work they do. Outputs are not the same as outcomes, which refer to the things you hope to achieve. For example, the output of a care agency is the number of hours they spend providing you with a care service. The outcome for you is that you remain in your own home.
People who use services	Anyone who uses care services, whether you are in your own home, in residential care or in hospital. The NHS is likely to describe you as a 'patient', while the council and other care providers may also describe you as a 'client' or 'service user'. You may also be described as a 'cared-for person', in relation to your carer.
Procurement	The process by which organisations such as councils find and pay for things such as goods and services, check that the service can genuinely be provided, and make sure that money is well spent.
Stakeholder	A stakeholder is anyone with an interest or concern in Haringey Council services and business. Stakeholders can be any individuals, groups or organisations that are affected by the activity of these services or the management of the Council's business affairs.

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