Appendix III: Summary of Toynbee Hall coproduction report.

Please note that this summary has been produced by the local authority, based on the text provided by Toynbee Hall (the text has not been changed).





Independency or learned helplessness:

A co-designed day centre service model in Tower Hamlets

Oct 2020

1. Introduction

Toynbee Hall Research and Policy Team were commissioned by the London Borough of Tower Hamlets to:

- 1. Engage with a wide range of stakeholders, from service users and carers to providers and their staff, the voluntary and statutory sector;
- 2. Co-design a new service operating model for day opportunities services for older people which will operate for 3-5 years.

This co-design work explored the following questions:

- 1. Current service model:
 - what works well, what is missing and what can be stopped? How services can be integrated and what could be the flexibility of services?
- 2. Individual needs and experiences:
 - why individuals use the services and why they stop, what impact services have on an individual's independence, what users and carers want from future services, what is the impact of Covid-19 and what are the ways to mitigate it?
- 3. Eligibility check and direct payments:

 Where are individuals referred/signposted to when they do not meet eligibility requirement, what barriers are there for users taking a direct payment?

The focus of these discussions was on people's aspiration and desire for the future service model, and the service model demonstrated in this report has been identified and shaped directly by the participants. This process included the following three aspects:

- 1. Co-design with day centres
 - 5 meetings and 1 workshop with 5 day centres
- 2. Co-design with service users and carers
 - 9 workshops and 1 interview in English
 - 2 workshops and 8 interviews in Bengali and Urdu
 - 98 surveys
- 3. Co-design with stakeholder organisations
 - Workshops with organisations
 - Interviews with key stakeholders

Using this approach, we have involved:

- 12 day centre staff members
- 115 users and 26 family members (we call them carers in this report). See details in the chart about numbers of users and carers from each day centre.
- 18 stakeholders

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| Impact of Covid-19: The "shielding" and isolation has demonstrable impacts on users' mental and physical health. Users and carers noted that, while staying at home is a safety measure, they see "no quality of life" and users' conditions have deteriorated. | Users and day centres want the centres to re-open as soon as it is safe and possible to do so. If centres have to remain closed however, then support can be delivered as a tiered model. |
| Diversifying support channels: Day centres have applied different methods in supporting users during centre closures. | A tier-based approach could be useful in delivering outreach, telephone and online services. Users who are more comfortable with group phone calls or digital activities can make use of these centre-provisions, while other higher-needs users could benefit more from outreach visits and walks. |
| Independency vs. learned helplessness: A key learning was the need for services to "change the mindset" (stakeholder) of service providers. As stakeholders reflected here, are we supporting people to live in a "normal" and independent life, or are we creating a structure for "learned helplessness"? | We want a service that supports people to feel able and "normal" within wider society, not one that makes them feel different from the rest of the society or reliant on others. This means that (to name a few): Users can attend day centre for a few hours, rather than a full day or a half day. There could be a transport allowance in personal budgets Support in managing finance can be included in personal budgets, More support is provided for connecting users with other services and support. People can attend activities altogether, regardless of which day centres they are from, Users can have natural friendships outside the centre. |
| Reablement: Reablement should be at the core of service delivery. | People should be referred to universal services rather than day centres if they only need some support in socialising. For each day centre user, a set of meaningful goals needs to be identified and staff should support users to achieve these goals. Day centres should link up with occupational therapists. |

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| Contributing to society: Service users enjoy supporting each other in the centre and contributing to society through ways that they are able to. | Staff should encourage peer support in all centre activities. We recommend making it easier for users to contribute, be it to the centre or society in general. |
| Having ownership of the services: This refers to users and carers having a choice of activities and support, co-creating services, and playing an active role in evaluating service delivery. | A change of mind set is required so users and carers are not considered as receivers of the services, but the owners of it. They should be encouraged to steer their own paths, create ideas and play an active role in the delivery and evaluation of services. |
| Personalisation: Every user is different, and we can see that there is space to develop personalisation in the services. | Users and carers suggested that a wider variety of activities and support can be available for users so users can make a choice based on their interests and circumstances. These activities and support can be universal services, outside the day centres |
| Flexibility: Users and carers felt that they have good flexibility when rearranging dates in advance. However, they would like more flexibility attending the day centre, particularly if an emergency arises. | A future model could allow for emergency appointments, perhaps a set number of additional places at the centre each day for this. Having the centre operate on weekends could suit some users and carers better. |
| Who is providing care: Not only staff members and carers are providing care; users, volunteers, mutual aid groups and other community members can all be involved in supporting each other and providing care. | Partnership working needs to be promoted involving centre staff, users, carers, other community members, and in fact a variety of stakeholder organisations. |
| Staff members: There were numerous descriptions of the centre staff as "skilled", "thoughtful" and "absolutely brilliant" (users and carers). However, the professionalism and support provided by staff at specific centres remains a concern for a small number of carers. | Staff members should continue to maintain a high level of professionalism and skills. Even though day centres and the local authority have a comprehensive system in dealing with complaints, the system does not seem to work well for a small number of users and carers. |
| The need for building-based services: Currently there are five day centres across Tower Hamlets, and it has become a routine for current users to attend day centres. It is important to maintain a level of continuity so users feel safe and secure. In addition, we need to address the need to maintain a building- | In light of the Council's plan to reduce building-based services, we propose to maintain three buildings: - One building will provide specialist service for people with dementia; - Two buildings will serve as both generalist static centres |

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| based service for those with severe mental illnesses. This was reiterated by many users and carers, especially those with dementia. | and "activity hubs" which could be the meeting points for community-based services The priority for building spaces could be reserved for users with a higher level of needs, but with the choice available for these users to attend community-based spaces, supported by a carer Have staff who speak local languages including Bengali Able to provide culturally appropriate food A range of different activities should be provided to users in order to suit different needs. Located in different parts of the borough Fully accessible disabled toilets with changing places and hoists etc |
| The need for community-based services: Many users cited how the opportunity to go outside of the centre, whether for fresh air during walks or visiting new spaces like museums, was an enjoyable aspect of using the day centre. We have also noted weak integration between day centres and universal services, such as Linkage Plus and community spaces, even though some universal services in fact provide better holistic, specialist and community support. | A dedicated group of staff and volunteers can coordinate and support a number of interests groups outside the centre buildings. These activities will be identified by users' interest. All building-based and community-based activities can be organised in a set schedule (e.g. unchanged for 2 months) so users can follow a routine that they choose. |
| Integration of services: There is a need to improve integration between day centres and other services. For example, home care services, occupational therapists and physiotherapists were often talked about in our discussions with users and day centre staff. Better collaboration will ensure all services better support the users. | It was suggested that key stakeholders can establish a working group and meet in monthly meetings. |
| Accessible toilet facilities: The lack of free access public toilets has been an issue for Tower Hamlets and many other boroughs. There are only a small number of places where fully accessible disabled toilets are available. This prevents users from accessing community spaces for long periods of time and | Community activities and interest groups can be organised for a few hours a day so toileting will be less problematic. We can stratify the model into tiers, where lower-needs users could make use of public, disabled access toilets or ordinary public bathrooms, and higher-needs users could make good use of the static centres |

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| is an obstacle to a community-based services model. | which would need to have fully accessible facilities. More importantly, local authority should work with idea stores, leisure centres, community organisations and businesses to increase fully accessible disabled toilets |
| Transport: A common issue for many users is the time it takes to travel to day centres | A combination of council/centre-dedicated buses and self-arranged transport should be available for users. We recommend that for the day centre users, council or centre buses should be maintained to support some users especially those with wheelchairs and a higher level of dementia. In addition, self-arranged transport should be encouraged and supported by personal budgets. |
| Inclusive services: There was a strong interest from all users to mix with people from different ethnicities, although language barriers remains a concern. There is a divide among the Bengali community about whether segregating men and women is essential. An overall perception was that people over 60 are happy to mix with each other, and younger users may choose to withdraw from building-based services if the majority of users are over 60. A general perception was that people would welcome mixing people with early stage dementia with other users, and would prefer users with advanced dementia to have their own day centre | Users will welcome culturally appropriate day centres. Centres can provide culturally appropriate food and encourage users to share food from their own culture. This would help users feel at home and allow people from different ethnicities to learn about each other's culture. Barriers in terms of communication could be addressed by having staff and volunteers who can speak local languages to help facilitate conversations. Users should also have the option to choose how they arrange themselves at the centre in terms of segregating or not. Diversity should be maintained and encouraged. |
| Information about day centre service: Knowledge of day centre service for both prospective users and other health and social care teams is limited, and more could be done to raise awareness of the availability of services, especially as many are undersubscribed. | Promotion and awareness of centres is vital for potential users to receive the assistance available to them. Leaflets, for example, can be distributed through carers centres, GPs and local newspapers. |
| Information and support on direct payment: There is an absence of information, or substantial misinformation, surrounding direct payment and how it works. All users and carers we spoke to either did not know about direct payment, have been told there is a long waiting list for direct payment, or | We welcome the council's current initiative to promote direct payment and provide support on direct payment. Stakeholders noted that it is key to involve carers centres in the promotion, and they recommended that allowance can be allocated in personal budgets to enable users to receive ongoing support in managing |

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| did not know support is available to apply for it. | direct payment. |
| Referral: Referral seemed to be one of the most difficult parts of the user journey. | When people are not eligible for the day centre services, they should be referred, not signposted, to universal services. Users should be encouraged and supported to take up direct payment so they can access universal services with support. |
| Trust in services: There was a discrepancy between how service users viewed the day centres and how they viewed the council, even though day centres are fully funded and managed by the council. Service users and carers were largely praiseworthy of the help and services that day centres offer but were depreciative and dismissive of the works of the council. | The perceptual distance between the actual services and the local authority only reinforces the negative images of the council and social care; as such, more should be done to promote the branding of these centres, as funded effectively by the local council. Better communication and true co-production can also strongly develop trust between communities and local councils. |

In order to develop a future service that supports independent living, we have identified some key actions which can be implemented short term – to be considered under current service model - and long term for the new service provision. Short term:

- Local authority to provide information and support on direct payment, and include allowance in personal budgets to support people managing direct payment.
- Local authority to form a monthly working group involving day centres, brokerage team, social work team, hospital discharge team, occupational therapists and physiotherapists.
- Day centres to develop a tiered-based approach to deliver outreach, telephone and online support during lockdown.
 - Day centres to improve branding and distribute information on service provision.

Long term:

- Local authority to develop the hybrid model of building-based and community-based services.
- Local authority and day centres to include users and families in service creation and evaluation.
- Local authority to include transport allowance in personal budgets to encourage the use of self-arranged transport options, and continue providing council or centred-owned buses.
- Local authority (Locality Teams) and day centres to identify any gaps in the complaints system and work with users and families to improve it.
- Local authority to increase fully accessible disabled toilet facilities.
- Local authority to reduce paper-work and deliver people-centred support.