Patient Experience Team

Support for Tower Hamlets informal Carers

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Background and Introduction

In late 2019 the THT Board agreed that the next Patient Experience Team (PET) whole systems review would focus on support for informal unpaid carers (those looking after a friend or relative with support needs) living in Tower Hamlets. Interviews began with a small number of local carers, as well as the Local Authority (LA) Commissioner for Carers Services, and the recently appointed Chief Executive of the Carers Centre Tower Hamlets (CCTH). The team are also grateful to Healthwatch Tower Hamlets for sharing their review of carers services undertaken in 2018 / 2019 and which helped us to focus and build on their findings.

Unfortunately, our work was put on hold in early 2020 as the pandemic necessitated a reprioritisation of the focus of the PE Team, so the review was paused until February 2021.

Data available from the most recent census carried out in 2011 states that there were 19K people in Tower Hamlets who identified themselves as informal carers. It is estimated that this figure is likely to have risen by 30%, so would now be nearer to 24K including young carers.

The Carers Centre annual survey report (undertaken during October and November 2020) stated that one in twelve Tower Hamlets residents is an unpaid carer. The data also demonstrates that 67% of carers are aged 35-64; 67% are female; and 63% from an ethnic minority. Statistical analysis also shows that 23% of carers require a service in one of the following community languages: Sylheti, Bengali, Somali, Urdu and 32% have a disability or a significant health issue. (More recent data may soon be available through the results of the 2021 CCTH survey).

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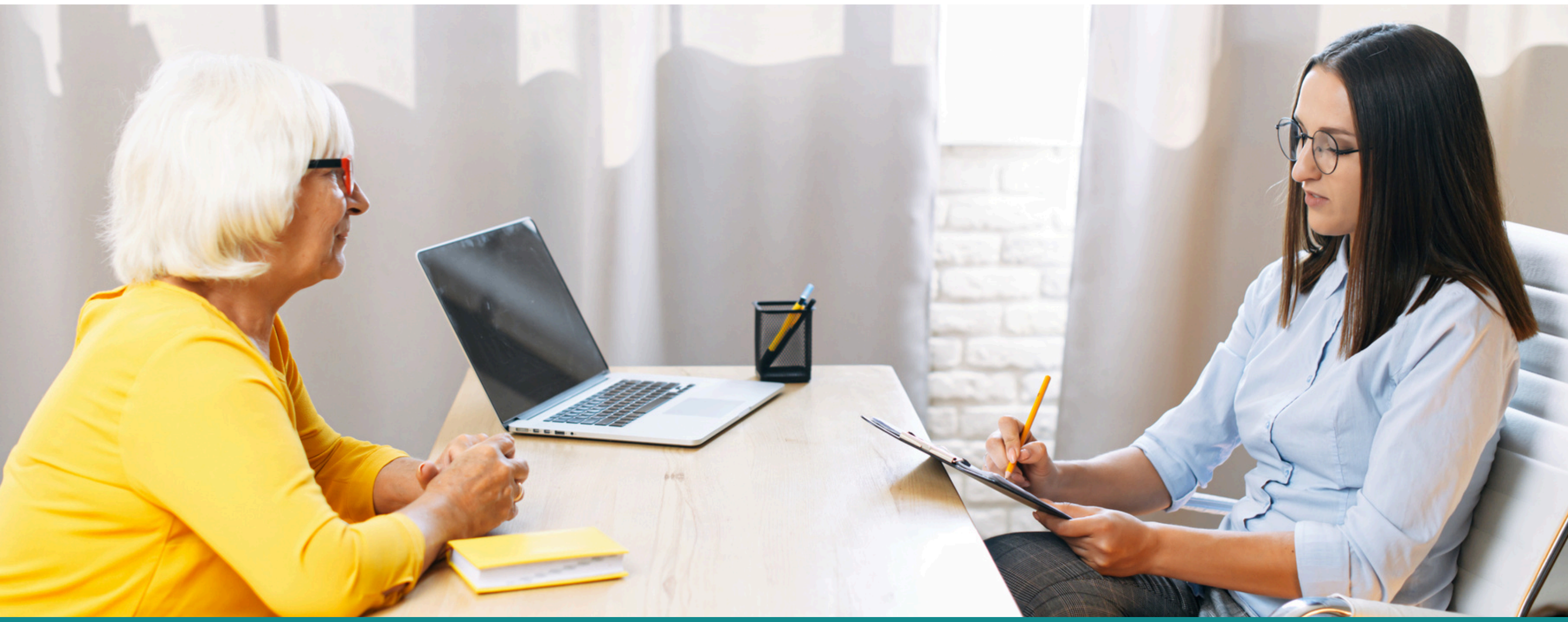
This data confirmed the importance of the PET looking in detail at the needs and support available to informal carers, particularly since the pandemic has created new carers and put additional pressures on those already identified as such. There have also been changes to both provision and availability of support delivered which make this review timely and significant. An issue currently under discussion, and a key finding of the PET Review undertaken last year which examined Admission Avoidance, is the need to provide more preventative interventions to enable people to remain independent within the community, and this is of significance in relation to informal carers.

There is also evidence to suggest that a proportion of carers either do not self-define themselves as such or feel that they do not require support in their role. There is, however, a sense that many carers perceive that the type of help they require is not available, so see little point in identifying themselves as carers. Some carers also feel they are expected to provide support to their relatives, so do not feel they are either presented with a choice or offered recognition of their role within their family and / or community. This was particularly the case among younger carers.



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Methodology

Analysis of data relating to the numbers of carers and cared for being admitted or readmitted to hospital was not available to the team at the point of writing the review.

The main approach adopted was therefore qualitative using the Discovery Interview methodology. The team found that asking for demographic data of carers impacted on the quality of the interviews, with trust being harder to establish and some evidence of caution about whether the interviews would be wholly anonymised, despite assurances. The team instead began asking for demographic information at the end of interviews, but this was not always forthcoming.

The team faced a further challenge in that carers were less willing to talk to us about their experience, and this will be discussed in detail in the body of the review but relates in part to a belief that the recommendations made will be unlikely to lead to an increase in support made available to them.

Data relating to the initial uptake of the 24- hour emergency support available to carers through Age UK East London suggested that this service was being under-utilised when compared to the extent anticipated, and this was seen as likely to be due in part to the criteria originally excluding those carers already in receipt of support combined with fears about allowing potential Covid infection into the home. A further extension to the pilot and relaxation of the criteria for eligibility has not, however, led to a significant increase in uptake, so this service is currently under review through engaging in coproduction with carers.

Data relating to any increases in concern around safeguarding resulting from pressures on carers were also hard to identify, as the status of being a carer is currently unlikely to be recorded. Similarly, those being referred to mental health services such as Talking Therapies are unlikely to be logged as carers as the focus, at least initially, will be on the mental state of the individual rather than their status as a carer. This makes it hard to ascertain the extent to which crises in mental or physical health can be linked to the role of being an informal carer, or whether the absence of timely support leads to the breakdown of the caring situation.

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Challenges faced conducting interviews

One issue concerned talking to carers about their experiences while the PE Team were working from home (WFH). A long-established key principle adopted by the PE team to enable the interviewees to feel as comfortable and safe as possible while sharing their stories involves the interviewer visiting the person's own home or meeting at their chosen neutral space. This approach has demonstrated that in-person visits enable trust and rapport to be quickly established and result in people feeling more comfortable about sharing their often emotionally challenging experiences. However, in the case of informal carers, this required the person being cared for to be in a separate safe place to enable the interviewee to share their story in an uninhibited way, without feeling anxious that raising any negative experiences of caring would not impact adversely on the person they look after.

Previously, the team would arrange to visit when the cared for person was not present or when they were being looked after by someone else, but as most of the time the person would be in the shared home during the pandemic, this made it harder to find a space for the carer to talk alone to the team, whether digitally or not, and this resulted in many carers turning down the offer to be interviewed.

As has been widely recognised, digital and remote communication itself can create barriers and for those who are not digitally connected, landline telephone calls with no visual contact can make communication harder still. Where people have sensory or other barriers to communication, face to face contact enables utilisation of various methods to aid mutual understanding, such as speaking more clearly, at slower speeds or at greater volume, or repeating or finding different words or ways to frame or phrase a question. These methods can all help overcome barriers that may present themselves when using remote contact methods. There is a certain tension that results from having to constantly repeat 'pardon' when a person cannot hear and/or understand a question over the phone that can more easily be diffused in person.

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Challenges faced conducting interviews

Another challenge encountered by the PE team has been a reliance on those organisations working directly with informal carers to help make initial contact. Previously, a general call out through these organisations would result in many potential interviewees making direct contact with PET to share their stories. As most organisations were working remotely at the height of the pandemic, the team ‘piggy-backed’ their virtual meetings in order to reach carers, but it became apparent that in some cases there was a degree of reticence amongst carers about sharing their experience, and this may in part be connected to lack of confidence about publicly voicing their views but also a fear of potentially losing existing support should the team ‘shine a light’ on a service they value during a time of scarce resources.

Where contact was facilitated in virtual group meetings by host organisations, while very valuable, this is not always conducive to people sharing individual stories and it can be hard to approach individuals who are on Zoom or Teams to offer 1:1 interviews at a later date. Whereas in a face-to-face group meeting, the facilitator will be aware of body language and non- verbal signals to indicate a desire to speak, these visual clues are difficult to pick up in a virtual meeting, and it was evident to the team that remote meetings make it far harder to pick up on the more subtle signals and to promote inclusivity.

Another equally challenging issue was the tendency for some organisations to tightly control meetings, and on occasion discussion around unmet need was inhibited. This could largely be due to time constraints, but equally could reflect a concern that issues raised might reflect adversely on the function or service provided by the organisation. As the voluntary sector are often in competition with each other regarding the awarding of contracts, this can create a tension or commercial sensitivity between organisations which may have worsened since most meetings are remote, and it is harder to have honest partnership-promoting discussions on a more informal basis.

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Challenges faced conducting interviews

Finally, towards the completion of the review, at a face to face facilitated meeting hosted by a voluntary sector group, carers directly expressed their anger about changed needs and unmet support, and lack of recognition of their role. These carers were very sceptical about whether their contribution to the review would lead to any improvements in the support they received and felt that investing time in talking to our team was actually of little value. Although the group referenced some positive outcomes that directly resulted from previous reviews (for example, since implementation of one of the recommendations from the Foot Health Review, Foot Health have been delivering training sessions for carers at CCTH which have had very positive feedback) however, the overall mood was of hostility, despondency, and anger.

Summary of key issues

- Carers universally appreciated the alternative and imaginative provision offered by Russia Lane Day Centre and this presents an opportunity for learning and roll out of a similar model should future lockdowns prove necessary
- Carers who find themselves in a situation where they need support may not always be able to identify how to access help and what form that support might take, so more proactive, sensitive, and tailored approaches are required (as explored in some detail later).
- CCTH and Voluntary sector organisations were quick to adapt to the pandemic and to explore and implement creative ways to deliver alternative forms of support, but investment is needed to enable capacity to respond to increased demand

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- Availability of regular planned respite was perceived as being extremely difficult to access, so communication around respite needs to be improved to counter the perception that such preventative regular support interventions are a low priority both during the pandemic and going forward
- Several carers felt that the pandemic presented cash strapped organisations with an excuse to limit support as they had been perceived as coping well without it during lockdown
- Several carers felt that there was too much reliance on informal support being provided by friends and family networks, and were concerned about the impact of this on their relationships as well as raising potential safeguarding issues
- Some carers felt that there was a need for specialist understanding of support needs by condition that would be challenging for CCTH to meet without additional resources being made available
- Several carers felt that while Direct Payments are appropriate and liberating for some people, other see regular support provided as part of a package would better enable them to have time to themselves without the additional stress of having to organise their own support
- Investment in voluntary sector groups is vital to enable them to provide a range of pre-crisis opportunities and activities for carers and those they care for to enjoy either individually or together. The tendering and procurement process means however that irrespective of whether carers feel that an organisation is valued and meeting their support needs, due process requires that the service needs to be retendered, although some carers experienced changes resulting from this as destabilising.
- Lack of available data makes it hard to evaluate the pinch points and most appropriate areas to invest in provision of support and interventions to prevent crises

Key recommendations

- THT to support the gathering of, sharing and access to system-wide data for future reviews. There are likely to be strong financial arguments within the integrated care system for more preventative interventions, however, due to difficulties in accessing quantitative data across the system, it was not possible to conduct an analysis of the costs associated with timely interventions to prevent the breakdown of caring situations.
- Should future lockdowns be necessary, a more systematised approach to maintaining contact with carers should be adopted. Carers appreciated the proactive contact made by some organisations during the pandemic, and felt this regular check-in helped them to feel they had not been abandoned and so enabled them to continue in their role.
- Assumptions that informal family and social networks will provide carers with ongoing and regular breaks are not always appropriate or safe. Support offered should be approached in the context of safeguarding issues and with provision to assess competence and aptitude of those offering and providing support to informal carers
- ·Carers issues should be at the forefront of each of the Life Course workstreams, with representation from organisations with specialist knowledge of carers issues and those with lived experience of informal caring
- ·Evidence suggests that investment in additional Early Intervention roles in MH would help prevent future crises for those experiencing their first episode of psychosis through supporting both patients and informal carers/family members
- Opportunities to raise awareness of psychosis could be explored via existing training opportunities such as the Carers Academy, CEPN and MH training networks.
- Local knowledge and expertise is critical when commissioning services, and opportunities for key TH organisations supporting carers to come together to identify what support is being offered as well as gaps in need and potential for improved joined up working should be created and facilitated on a regular basis

Key recommendations

- A mixture of generalist and specialist services would acknowledge the specific needs of a wide spectrum of carers and would not necessarily represent duplication of services. Although previous codesign and coproduction recommended that a single service would reduce the need for carers to re-tell their stories and reduce hand-offs, there was evidence of a shift in thinking by many carers who participated, and a favouring of some specialist service reinstatement.
- ‘Little and often’ support is highly valued and likely to prevent the breakdown of caring situations so provision should be invested in and seen as taking priority over crisis intervention
- There is an urgent need to identify and support young carers who are currently suffering a high degree of mental health issues and limited life choices through lack of recognition of their role and consequent pressures experienced. Key to this would be to identify funds to reinstate the minibus formerly provided to enable young carers to attend support groups

Background

During previous whole systems reviews undertaken by the PET the issue of support for informal carers emerged as a frequent theme, with reports of carers struggling to access timely support and limited recognition of the challenges faced. This was particularly the case in relation to accessing continence aids and foot health support for themselves and/or those they care for, as well as a being an issue that emerged during the recent review focusing on hospital discharge and admission avoidance.

PET obtained agreement from the THT Board in late 2019 to focus their next piece of work on reviewing support for informal carers and began talking to individual carers just before the pandemic impacted. The work was paused until February 2021, at which point it became evident that there were several Covid-19 related issues that contributed to the work being considerably more challenging than previous reviews.

Background

Capacity and morale

As voluntary sector groups are expected to provide an increasing range of support for ongoing health and wellbeing to informal carers, there will inevitably emerge some challenges around capacity to deliver unless there are additional resources allocated to meet changed need. Increased expectations amongst carers who have developed good relationships with these teams may lead to more frustrations with the organisations who may be perceived as being expected to but often unable to meet all their needs. The voluntary sector is often in a key position to forge relationships with carers and so have a sense of when a carer may be experiencing increased stress. This regular contact enables timely provision of or signposting to a range of interventions to prevent the breakdown of the caring situation, which is likely to prove a more cost-effective strategy than intervening when possibly carer and/or cared for require hospital admission or intensive long-term support.

As will be explored in some detail later, there is also an issue relating to some people being reluctant to accept the label ‘informal carer’, and much work is underway by the LA facilitated Carers Working Group (CWG) to address this. There is also wider encouragement of dialogue across Carer focused organisations to look creatively at ways of describing the caring role. The aim is to promote recognition of the importance of the contribution carers make in supporting another person, but this is a challenge if some carers regard this role as a duty rather than a choice, and while there exist perceptions that support is unlikely to materialise. The emphasis on identifying more carers comes at a point where many organisations feel they are already working to full capacity in supporting existing carers, so without an injection of additional funds there may be reluctant to identify and signpost more carers to access already stretched resources.

Objectives

The review will:

- Explore the impact of the Covid-19 pandemic on informal carers, including those who became new carers during this period
- Identify support available to carers, including through informal networks, voluntary sector and peer support, as well as more formal service provision
- Explore ease of access to support and better understand the stage at which people identify as ‘carers’ and actively and accept help
- Identify any areas of unmet need
- Explore the outcomes of the current polices and resource allocation across the system in relation to carers and identify any pinch points and consequences of untimely provision or deficits in support
- Use learning to inform commissioning and service development

Methodological approach

There are two discrete approaches intended in the review: qualitative in-depth interviews and quantitative data analysis.
The review planned and endeavoured to include an audit and analysis of quantitative data relating to admission, discharge planning and readmission of those being cared for, as well as any instances where both carer and cared for were admitted to hospital. Similarly, uptake of emergency interventions required in the community and resulting from breakdown of the caring situation were also regarded as key elements in understanding what pressures were being experienced across different points in the system. However, attempts to access this information were unsuccessful, largely because it appears that the status of being a carer is seldom logged across the system.

Qualitative and anecdotal information was however provided by frontline staff across a variety of organisations as well as individual stories and experiences shared by carers themselves, and these indicated that while some support plans were implemented successfully, on occasion poor or untimely discharges or delays in accessing community support did indeed lead to breakdown of the caring situation and on occasion, readmission or admission of carer and cared for to hospital.

Objectives

Qualitative methodologies were used to gain carer and provider experience using Discovery Interviews, which are effective in enabling engagement in direct dialogue with respondents and facilitates unpacking of views. In qualitative research, the main interest lies in identifying and describing the range of issues, themes, views or experiences and the relationships between them, rather than counting or estimating their prevalence. The work is in-depth and detailed as opposed to standardised and large-scale. Sample units are thus relatively small since there is a point of 'diminishing return' or ‘saturation point’ where increasing the sample size no longer contributes to the evidence. Thus, the sample does not need to be large enough to support statements of prevalence or incidence since these are not the concern of qualitative research. It is also impossible to do justice to the richness of the data yielded if the sample is large-scale.

There was also a significant variation in anecdotal reporting of satisfaction with levels of support received that was communicated in feedback obtained during lockdown when compared to a later stage in the review. It was evident that earlier in the engagement process carers assumed that as lockdown restrictions eased, there would be a return to pre-covid levels of support, so were reporting that they felt they had managed reasonably well initially.

However, as the pressure on available resources has continued and intensified, the emphasis on empowering and enabling people to manage their own situations and in some cases, assigning resources directly to carers to promote an appreciation of the need to demonstrate value, has led to a notable shift in the levels of satisfaction and more evidence of increasing frustration and pressure reported by carers.

Objectives

- In the case of this study, a qualitative methodology was able to:
- Provide an opportunity for carers to tell their stories and share experiences
- Enable an understanding of the themes from both a provider and user perspective
- Allow an exploration and ‘unpicking’ of the different factors that have created either previous positive or negative experiences/opinions and how they might be interlinked
- Provide a mechanism through which aspects of service provision can be explored through the perspectives of commissioners, service providers and carers participating in the review
- Provide a mechanism through which aspects of service provision can be explored through the perspectives of health and social care professionals
- Enable an understanding of the nature of the role of health and local authority / voluntary care professionals in the process of supporting carers
- Enable an understanding of the interplay between health and social care professionals and carers in relation to self-care strategies.

It was considered that the most suitable qualitative methodological tools for this project would be individual in-depth Discovery Interviews, however in addition there were several facilitated group discussions, mostly conducted via Zoom or Teams and hosted by partner organisations providing direct support to carers and / or those they care for.

Between February and October 2021, 57 informal carers agreed to share their views.

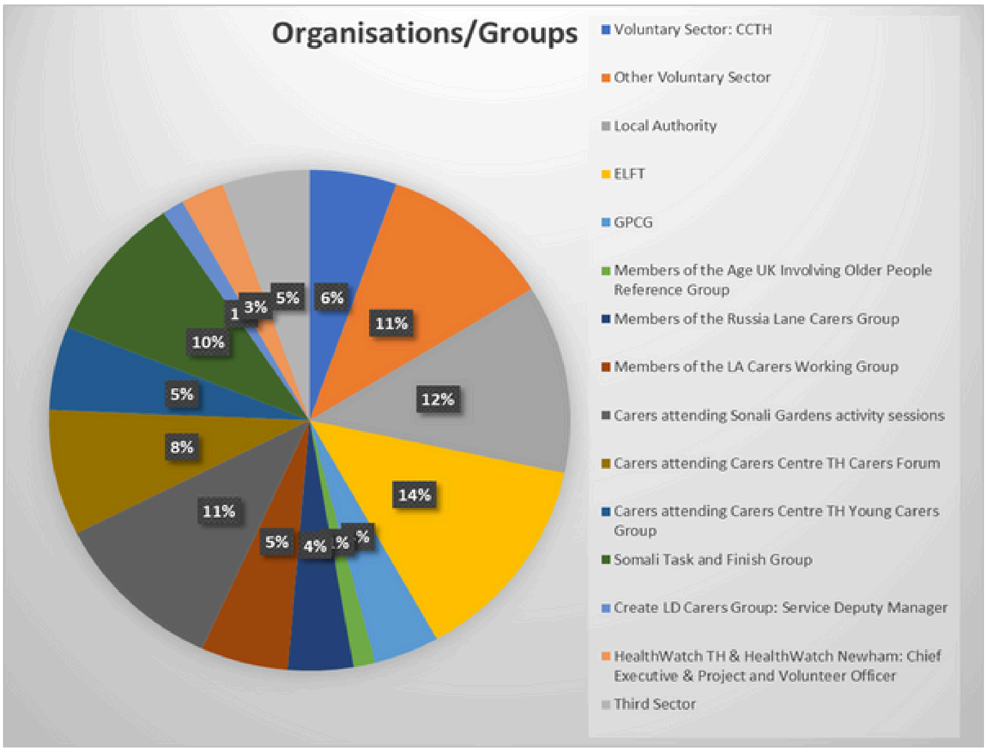
Data Collection

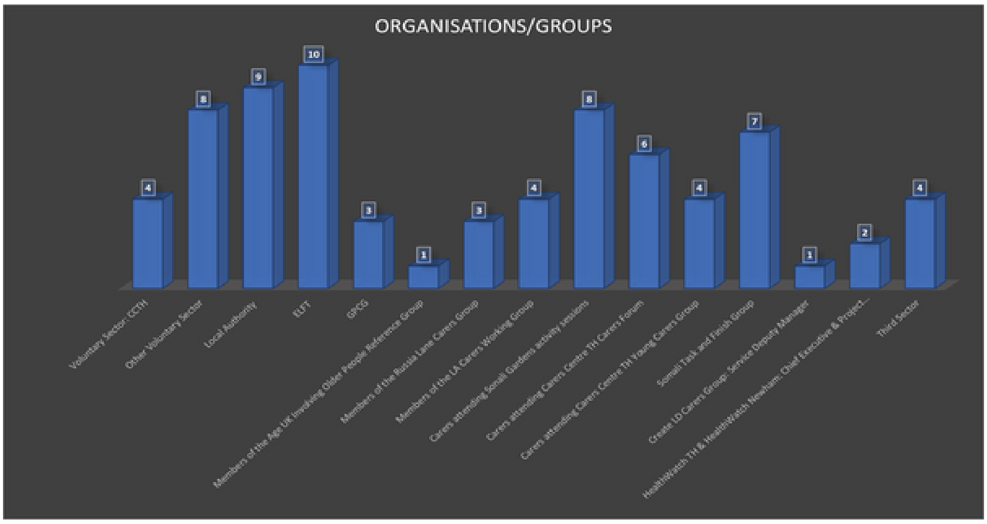
The Patient Experience Team and volunteers in the Discovery Interview team undertook the interviews which were digitally recorded and transcribed by an external provider. These interviews use a spine of open-ended questions developed by the Coronary Heart Disease (CHD) Collaborative as part of the NHS Institute for Health Improvement Agency in the early noughties. The Patient Experience Team also contributed to / facilitated the group sessions, and the Team Manager undertook interviews with frontline providers of services, Service Managers and Commissioners.

Data Analysis

Patient Experience Interviews
A total of 25 telephone calls were undertaken, with all participants agreeing to share their views by phone. Most carers who spoke to the team expressed a high degree of satisfaction with the support received, but many were unable to access support on a regular basis. There have also been some useful suggestions for potential improvements to the services provided. There were also facilitated group discussions with a further 32 carers who shared their views. Interviews were also undertaken with CCTH staff (4), Other voluntary sector managers (9), LA managers and commissioners (9) ELFT (5) GPCG (3), Barts Health (1)

Data Analysis





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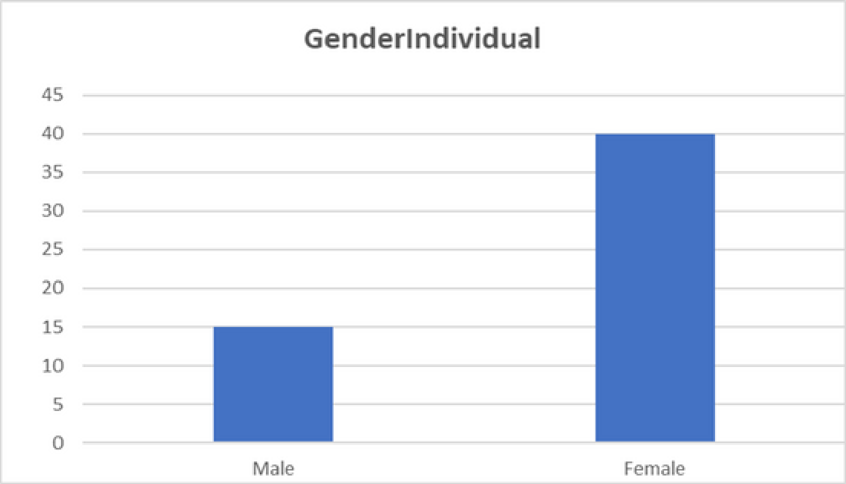

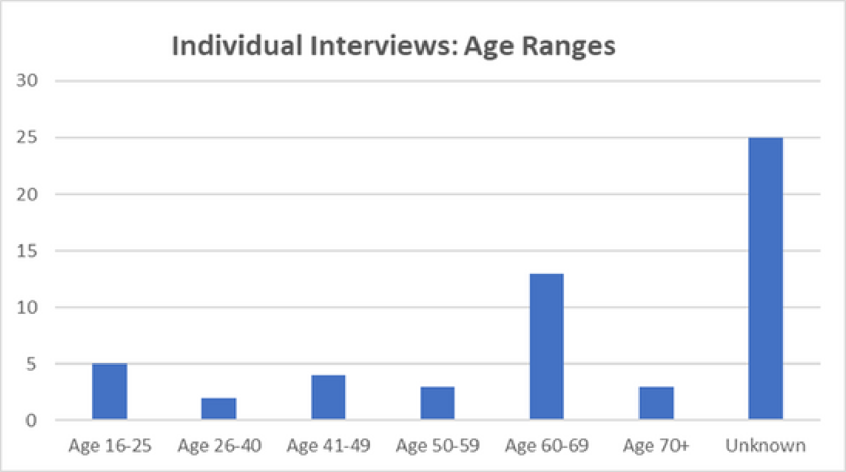

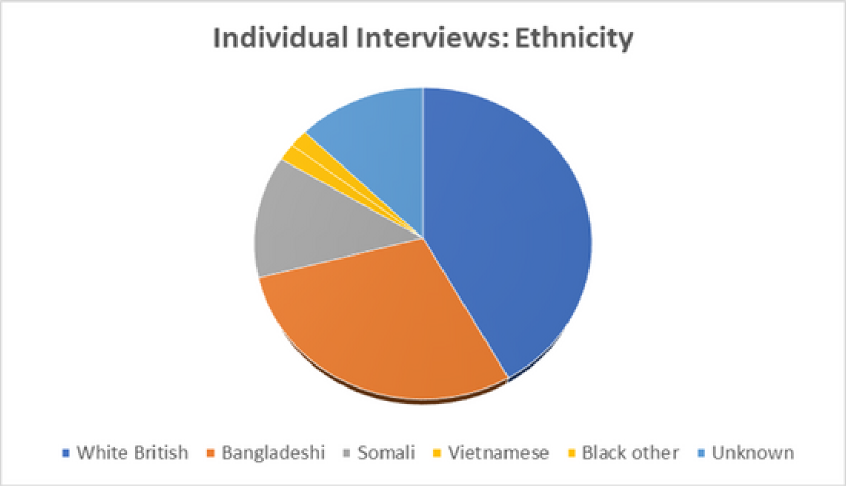

Discussion: Support for Carers

The Carers Centre (CCTH) is the key integrated commissioned provider of health and social care support to carers in Tower Hamlets, providing information, advocacy, casework, and Carers Assessments. CCTH also assist with benefits advice and grant applications to help maximise the income of the carer's household and the cared for person. Since the pandemic there has been a termination of several resources that were provided by specialist services, and a move towards a more generalist approach provided by the CCTH. This review aims to also look in some detail at the degree to which this strategy has been able to meet the needs of all carers, and the impact of these changes.

Another important aspect of the commissioned service provided by CCTH is the Carers Academy, which aims to educate informal carers to better manage their caring role and to prepare carers for life beyond caring. The Academy also provides general life skills via training such as manual handling and digital skills and the review aims to look at the way in which it has supported carers through a challenging time.

The pandemic has also had consequences in terms of supporting new carers and identifying previously unknown carers. The CCTH in-reach worker who, pre-pandemic was based on 11th floor at the Royal London Hospital (RLH) provides Hospital Carers Support (HCS) to existing carers, those who are becoming carers or whose caring role may have changed because of a hospital admission. This role being based within the RLH also ensures that colleagues within the hospital are aware of the need for close liaison with carers, particularly around planning discharge of the person being cared for. In addition, the HCS assists with arranging community as well as practical support, and helping signpost for help with housing, benefits, and adaptations issues. When the pandemic resulted in control of infection measures being escalated, the HCS in-reach worker spent over a year working from home in line with the RLH policy, and this necessarily impacted on their ability to connect directly with carers.

Reduced services

More recently this individual has secured desk space within the former discharge departure lounge at the RLH and is once more able to have a presence in the hospital. However, high levels of workforce turnover since the pandemic have impacted on the levels of workforce awareness of carers issues previously embedded, so the work has involved re-establishing the role and raising awareness with new colleagues in addition to providing support to carers.

Another key role assigned and provided by the Carers Centre is provision and facilitation of peer support. CCTH facilitate a range of support groups including culturally specific groups, condition and age specific groups and general access support groups across a range of settings. Many of these groups continued to meet remotely during lockdown but as with all services being delivered in this way, some people experienced digital exclusion. The CCTH was successful in securing funds to assist with the purchase of digital equipment to support carers, but the costs of connectivity and ability to access hands on training in using the equipment have been harder to deliver. However, as soon as it was safe to do so, CCTH resumed face to face meetings, which has been hugely appreciated by carers in the borough.

In the early stages of lockdown, packages of support previously delivered either in a day care setting or through home-based support was impacted on. Many centres had to close their doors and switched to virtual provision of activities, and support offered in the home was often declined by carers due to concerns about transmission of Covid-19. Although service provision was revised to support carers and cared for in a covid-safe way, many carers felt the degree of risk in accepting someone into their homes outweighed the necessity for help, so struggled on alone. There are areas of positive practice identified, such as that provided by Russia Lane Day Centre for people with dementia, and this is discussed in detail later in the review. Many voluntary sector organisations were praised for their efforts to continue to find creative ways to support carers, with many of these initiatives recognised as providing a lifeline to carers in enabling them to continue in their roles, and such examples of good practice will also be discussed in detail later.

Concerns around PPE and Covid-safety

Although many carers refused help during the early stages of the pandemic for fear of infection, those with responsibility for ensuring PPE was available to the workforce in the borough had, through forward planning, been able to quickly stabilise supplies. This helped to ensure that TH care staff supporting informal carers were able to provide a Covid-safe service in people's own homes, although the fear among carers that PPE would be inadequate meant that relatively few had the confidence, at least initially, to accept support. There were also some services that were unable to continue to deliver day care safely in a group setting, for example where the client group would be less able to adhere to social distancing. As the Carers commissioner explained:

> "From a carer perspective, where support services were not utilised due to anxiety about potential infection, we completely appreciate that carers had to take on a more intensive and involved role, however, the council never denied access to alternative support provision, although the onus tended to be on the carers to come forward and request alternative support, and the council would then explore various options."

These options included where someone had previously accessed day care service support, instead a Direct Payment could be provided to enable carers to explore other ways to meet support needs. However, the degree of anxiety amongst carers meant agreeing access to any person with the potential to bring covid into their homes was denied.

The Carers Centre were quick to raise awareness of the impact of the suspension of day services on carers, and this led to a more proactive attempt on the part of the council to identify those who needed urgent support and activate Adult Social Care to work with these carers to put in place alternative arrangements. However, such were the concerns about perceived risk, several of those identified as requiring urgent support requested suspension of or reduction in care packages. This prompted the LA to make decisions about how care could be safely reduced while ensuring the top level of need was met in an effective way.

Concerns around PPE and Covid-safety

Initial mapping revealed a particular hesitancy among those caring for people with complex needs, and carers of those with cognitive issues in particular identified worries about the amount of time it can take to build up relationships of trust and specialised knowledge of an individual, so under such exceptional circumstances, many preferred to decline the help being offered.

Hidden Carers

Another concern raised during the interviews was the realisation of the number of new informal carers taking on the role either during or as a direct result of the pandemic. How to identify and support these people proved challenging:

> "This was not just those caring for people with long Covid, but also people having to step into the role of carer who might previously have either had a paid carer going in to support them or have been able to care for themselves. It is also more than being about carers undertaking physical tasks to support a person, but also those providing support for mental health and emotional wellbeing …. those helping someone to access shopping and paying bills, and ensuring practical tasks are addressed in addition to managing their own households, and this can add to the strain carers experience.''

This drive to identify new carers or those in different and increasingly responsible roles accompanied a re-evaluation of the language used to define informal caring, as often the person supporting the cared for is not living with or a relative of the person they support, and in many cases are friends or neighbours. This desire to encourage language change resulted in new approaches to engage with people in a caring role to enable self-definition. The emphasis focused on encouraging assessors to explore whether there is someone who depends on the person, and this reframing of the conversation aims to enable the person undertaking the activities and providing the support to think differently about who does depend on them, and in turn to encourage discussion about different forms of support available in a timely way.

This engagement also aims to create a dialogue whereby the LA can have an honest exchange about offering help or support only at a time where the carers identify it as being appropriate. It is also intended to be more effective to frame the carers assessments in terms of assessing what a carer needs to be able to continue in their caring role, although many carers shared with the interviewers that they felt there was little support offered or provided unless they identified themselves as being in a crisis:

Hidden Carers

“I know support is what they advertise as being available, but to physically access it and take up the offer is not that straightforward, you know? Each time you called somebody during lockdown it felt like there was no one to help you and everything was shut, the offices and centres… who was going to talk to me? I’m thinking there are people out there – carers like myself and maybe they need more help than me, and I feel like I have no one else to help me out. I did get upset and felt alone.”

’’The agencies I thought would help and support me weren’t there, I got my support from voluntary services and volunteers not the NHS or council.’’

’’The NHS just sent you to the local authority. It felt like no one wanted to help us.’’

An Age UK OPRG member who cares for a friend shared that they only realised they would be classified as a carer after attending a meeting relating to this review. This led to the carer saying that primarily they identified as a friend as they felt that defining themselves as a carer would change the dynamic between themselves and the person they supported. They also felt that as a friend they had a choice about the level of input provided, and voiced concern about the expectations that may accompany defining themselves as a carer:

“I am aware that the person doesn’t have any family, never married and although they have more friends than I’ve had hot dinners …they don’t live nearby… also, most of their friends including me are equally elderly, so it is hard. We were sitting in Moorfields after a diagnosis and the person I look after said ‘I’m so sorry because it means that I probably will have to be a bit more dependent on you than I want to be,’ so clearly the change is hard for them too!”

Hidden Carers

Another carer explained how she is looking after several people who rely on her for support, but has not identified herself as a carer formally:

> "I care for four people altogether, all friends and some full time; one person is blind and has no sight whatsoever, one has severe mental health issues and cerebral palsy, and another friend who had a stroke. But I'm not recognised by anybody as a carer".

Several people caring for friends found support difficult to access and felt that family carers are given priority over friends, and this lack of acknowledgement of the caring role can potentially have serious consequences:

> "If I try and phone the mental health services, I get told, 'We can't talk to you because you're not family.' When he was going through a crisis a short while ago, I was getting his sister to phone the crisis team because nobody would come out to visit. When they did send somebody, they sent an ambulance who he wouldn't let in. I just said to them,
> "Look, if you're going to do that, you could have phoned me."

Identifying new carers

The vaccination programme has also been a way of identifying those carers previously unknown to CCTH. Initially the Council focus was to reach out to carers most likely to meet the eligibility criteria; not known to GP services and not in receipt of Carers Allowance. The Council worked in partnership with CCTH and as the pandemic prompted a crisis in many caring situations where previously no support had been needed this resulted in many carers who were previously under the radar contacting CCTH, as the Chief Executive explained:

> "CCTH set up a registration page and identified a few previously unknown carers… and this year the census will increase knowledge of statistics relating to the carer population. Part of this is also about accepting that people are not always aware that they are a carer and provide a caring role, and some do not want any type of information, advice or support; they're just getting on with it, but at some point if there was a crisis or a huge change in need, that person could be coming through the doors and no amount of initial engagement would have got that person in touch with us prior to that."

The LA hope that going forward, through making additional efforts to explain why an assessment is being undertaken, it will result in higher uptake of Direct Payments and purchased support, which it believes can sustain the caring role over time. However, as the quotes from carers above make clear, this 'little and often' provision was felt by many carers to be largely unavailable, hence the tendency for people to reach a crisis before requesting help.

While Direct Payments can be used in many creative ways, several carers felt that their use to employ someone to give them a break was a step too far in terms of their existing stress levels, as they feared the relationship between employee and cared for would take too long to establish to give them any real peace of mind. Similarly, others felt that asking friends or family members for support to give them regular breaks would impact detrimentally on their relationships.

Identifying new carers:

There is also an issue about whether they feel able to place their trust in someone from their informal network to have the necessary skillset to adequately provide appropriate support. As the Commissioner pointed out, the Adult Social Care (ASC) workforce should be encouraging carers to consider more imaginative and different ways to support their needs, giving them choice and control over how they take a break.

A staff survey was undertaken by the council to identify the number of carers in their workforce and to understand their caring roles and responsibilities, and how they manage to balance their dual roles.

The LA is engaged in ongoing dialogue and uses the coproduction model with informal carers to understand not only the most effective way of defining the role, but also to identify what support has been important and useful. In many cases the crucial contribution of digital connectivity emerged as key to people feeling supported during the pandemic, but as documented widely, many on low incomes or who have health issues that result in communication challenges were unable to skill up or afford the contracts associated with digital access.

The issue of digital exclusion brought into focus inequality of access to various sources of support on offer, with those able to use Zoom or Teams benefitting from being able to build up rapport that can accompany having a visual connection with others, and those who are digitally excluded experiencing the pandemic in a very different way.

Voluntary Sector

Many voluntary sector organisations providing in person groups where carers would previously have been able to access companionship and support closed their doors during lockdown while they negotiated a way to offer services in a Covid-safe way. The voluntary sector has also been key to enabling people to access technology and to acquire skills and the confidence to use it, and to work safely. Many of those employees in the voluntary sector were also advised to switch to homeworking. However, the imaginative ways that these organisations used to maintain contact with carers were greatly appreciated. As part of this review, the PE Team were able to reach out and contact carers to hear their views, we have been indebted to these groups for their support. The challenge of being unable to see people at the various voluntary sector centres was explained by one manager:

> ''For me, not being able to open our doors for people was really hard, as one of the reasons that our service was set up was to help with the isolation that many older people and carers felt, so closing the doors felt like we were doing the complete opposite...''

Closures of voluntary sector and day centres affected carers in many ways. Those people with a learning disability or cognitive impairment often found it hard to understand why they were no longer able to attend and meet with their friends. Some of their carers reported a deterioration of communication skills during this period. The impact on the carer themselves was that increasingly the only person they saw during a 24-hour period is the cared for person, resulting in increased stress levels and loss of any social life of their own. While some alternative provision was made, this did not give the carer much time or freedom to do anything else, and often there were limited places the carer could actually go.

Voluntary Sector

Another issue that carers raised was that sometimes during lockdown there was not always an identifiable support service required. Previously, for example, when the cared for person was attending day care, the carer was able to visit a local voluntary sector group to engage in an activity. The closure of this voluntary sector centre during the pandemic and the switch to online support left many feeling isolated and increased stress. This inability to link with peers in a social and face to face context was the issue rather than requiring a specific support service, but the impact was to diminish their ability to manage the more stressful aspects of their caring role, as these carers explained:

’During lockdown I felt very depressed. I didn’t want to get up anymore. I used to go to the carers centre when I felt down as that way you could meet people who understand … talking to somebody is better than not talking …. when you get low.”

“People don’t realise…because you’re a carer full time, people don’t understand how much stress you’re going through… or how much you need to be somewhere that people know you.’’

‘’I wouldn’t be surprised if people had mental breakdowns, but for me, I’m more physically drained, it’s affected my physical health. Mentally I’m ok, I just don’t feel I have the physical strength anymore.’’

‘’Attending the Zacchaeus Centre was a real benefit and really helped me a lot, being able to see and meet people, including other carers, and to communicate, converse … it improved my mental health, and I had access to fresh air there as there’s a garden too. I was able to pray and attend activities, so it helped me a lot.”

“When you’re with and around other carers at the CCTH it keeps your mind fresh. They get other people coming into the centre, like speakers and singers to give us more support.’’

Voluntary Sector

However, there were pockets of good practice that carers felt were key in enabling them to continue in their caring role:

> “Personally, for me there were several organisations that supported me during the pandemic. The Tower Project continued to support me throughout lockdown with advice and reassurance and even offered a grocery delivery service … the Homeopathic Clinic which First Start runs as part of the Tower Project continued phone consultations and the Homeopath Practitioner continued to send remedies (via post) throughout the pandemic. Hotel in the Park, which provides respite, also rang several times to check if I was OK.”

Sharing views

As previously noted, there was some reticence amongst carers to discuss their experience of care and support with the PE Team because of a stated fear of drawing attention to their existing provision during a time of scarce resources. Several voluntary sector managers were aware of carers they were in touch with and encouraged them to contact us to share their views but declined the offer. The level of mistrust in the ability of our review to influence policy makers in a way that will bring about improvement to carers lives was also evident in the following quote from a group of carers who spoke to the team in October 2021:

“Some people won’t be happy with the report, will they?There will be pressure on you to amend it… that’s what I think… so what’s the point of consultation? We do not want it to be toned down…you could get quotes from 100 people, but they will find 1 quote to justify their actions regarding cuts to services”.

Specialist vs Generalist support

A cause of concern shared by one group of carers was the ending of the contract with Rethink, which was a specialist service for carers and/or of people with mental health issues. This was a joint CCG and local authority contract but in line with the move towards more services being delivered centrally through CCTH. The decision to end the contract was made pre-pandemic. It was felt by commissioners that as CCTH is well known to and trusted by carers, many who regard the organisation as being a first port of call. CCTH was therefore seen as the most appropriate vehicle to deliver more generalist services. There is the aspiration that by centralising provision there is less likelihood of duplication of services. Similarly, some ‘flexi-carer support’ services previously provided through voluntary organisations such as Age UK East London were decommissioned in favour of localised provision of support as part of the generic personal home care packages.

Age UKEL delivered an extended pilot stop-gap service to unpaid carers across the borough who experience a point of crisis. This service provided 24 hours of care to use flexibly over a period of 12 weeks. Those in receipt of the service agreed to a carers assessment undertaken by CCTH to determine ongoing support needs, which could include support from ASC.

At the initial point of writing the review, use of the pilot service had been minimal so it was agreed that this pilot phase would be extended as the pandemic was believed to have impacted on take up. There was also some new flexibility introduced around eligibility criteria, as originally this service was targeting informal carers who are not previously known to Adult Social Care or health services, but as is addressed at other points in the review, while identifying new carers can be a challenge, ideally identification would take place pre-crisis point. The service now offers a more flexible approach to enable carers to have one off support, for example, if the carer is unwell.

Specialist vs Generalist support

The rationale behind the prioritisation of new carers not known to Adult Social Care or health services was intended to ensure that those least likely to already be known within the system and those with no formal support in place were able to access the service in a timely way. As the Carers Commissioner explained:

> "If someone is already getting three hours a week, but actually they need another two hours, they should be able to work with the social care team and have a flexible care package, and this is not the sort of emergency intervention the service is aimed at".

However, carers reported that accessing such additional support was not always straightforward, as when they are experiencing a crisis or are feeling unwell, they may be unable or unavailable to contact the social care team to organise more input at short notice.

The decision to replace what was described as traditional 'sitting services', such as that previously delivered by Age UK and Apasen and provide alternatives through home care packages came out of a desire to replace what was regarded as an outmoded passive model with options that provided something more meaningful and active, so that the cared for person is offered stimulating activities in the absence of the carer. There was also recognition that people need flexibility and represents a resistance to more rigid service provision which is viewed as being overly focused on delivery of measured outputs:

> "There is too little emphasis on long-term outcomes and giving people choice and control over support they receive, so part of my role is the Digital Portal roll out which acts as an information and advice suite of online pages, and a marketplace of providers where people can purchase their care directly."

Specialist vs Generalist support

This more flexible approach is aimed at allowing those carers who have had an assessment and are eligible for services to start accessing Direct Payments by default and aims to empower carers to use their annual or monthly budgets in whatever way they choose, including directly purchasing care. As the commissioner explained:

> "There is evidence to suggest that if a person can purchase their own support, they exert considerable care in tailoring the services to ensure the best possible outcomes for their individual circumstances."

Direct payments are being encouraged as a way of maximising the income and options on offer to carers and payment can be loaded onto a pre-paid card to purchase the support required through the marketplace of approved local providers, with a view to enabling carers to feel confident security checks having been completed prior to their inclusion on the list. Individuals and agencies listed in the marketplace will be regulated and subject to due diligence and quality assurance processes, however, the issue of recruitment and retention of care staff is impacting on most agencies providing support, and people are reporting that new packages of care are proving challenging to set up.

One carer shared their view about the challenges of obtaining specialist support cover for the person they look after who has highly complex needs:

> "Direct payments are great for some people, but my son has very complex needs, as he has a physical disability and mental health issues … We had carers we didn't know turn up when the regular carer had taken 2 weeks off and didn't tell us, so the agency sent somebody else. Then one of the managers turned up and wanted to come in, with no warning, and I refused because my son's anxiety level was high. They wanted to check the books were filled in properly and make sure the fire safety stuff was in place… Direct payments do give you control, but the biggest hassle was, although my son has been brain damaged from birth, we had to go through 6 terms of reablement to prove that he couldn't look after himself so we could then have the Direct Payments."

Specialist vs Generalist support

Other carers voiced similar frustrations about the need to repeatedly demonstrate support needs through assessment by Reablement in order to access Direct Payments, where they felt the cared for person's condition made it very clear that they had ongoing needs.

In addition to accessing the marketplace of approved providers, the Portal includes a list of local activities and events on offer, such as yoga or exercise classes, and activities aimed at vulnerable people will include stringent checks to ensure quality and safety standards are fully met. The support provided will be evaluated in terms of 'value for money', and both the costs of supporting the carer to have a break and the costs of the activity the cared for will attend are considered when ascertaining whether the support package represents an effective use of funds.

However, although this model sounds positive and empowering, it has been met with dismay by some carers who described having felt happy with the previously received regular provision from more traditional respite services in their homes. The expertise of the care staff and opportunity to build up relationships over time were regarded as offering a preventative and sustainable arrangement that put less pressure on them. Some carers at the Carers Forum shared their experience:

"When we felt stressed, we could carry on as we knew that a break was coming soon, without having to make the arrangements ourselves".

"We end up supporting each other. A carer we know is at home 24 /7 and looks after a loved one who has no idea what is going on… wakes them up every hour day and night. There was no reaching out to people by services … the carer was too exhausted to request help, so it got to the point where they could no longer manage and told the LA they needed respite immediately. They had to threaten to drop off the cared for person at social care and leave them there permanently. If it wasn't for front line support like Neighbours in Poplar and Sonali Gardens …. we carers had a WhatsApp group and that helped keep us going …God knows what we would have done otherwise…''

Specialist vs Generalist support

As provider organisations change, there is a planned ‘knowledge share’ that aims to ensure continuity of service from a carer perspective, and much planning went into the handover of the Rethink function to CCTH:

> “It’s around managing the delicate relationships between the outgoing and incoming provider … some may not be so willing to engage, but I know for example that CCTH and Rethink developed their relationship for over two years, so when the Rethink contract expired, there was a focus on ensuring a unified approach irrespective of the handover of responsibility to the partner organisation, because as providers of support, they acted in the interests of carers.”

Although clearly presenting a challenge when winding down a service, the willingness to share expertise and knowledge across organisations is seen as key to continuity and provision of quality services. In the case of the handing over of responsibilities previously delivered by Rethink as a specialist MH organisation to the more generalist service provided by CCTH, there was a degree of anxiety expressed by both partners and carers alike.

In addition to the challenges of caring, the organisation felt that the stigma associated with mental health prevalent in society requires a specialist and sensitive approach and tailored support. As one of the team put it:

> “When your neighbours and everyone in the community know that somebody in your family is dying with cancer, everybody comes round and can’t do enough for you.But when they hear that your loved one has schizophrenia, everybody runs a mile!”

The belief that specialist support is what carers need is echoed by carers themselves who spoke about the importance of loss of peer support with the more generalist approach. There was also frustration expressed by carers around the media attitude to raising awareness of the importance of mental health at the same time as the implementation of savings having to be made. As one shared:

Specialist vs Generalist support

> "It's counter intuitive. Every time I hear Boris Johnson and the media go on about mental health and, "Oh, it's so important!" part of me just feels like it's all a big lie".

Rethink expressed particular concern about the anticipated impact of the pandemic and associated rise in mental health issues which meant there was considerable lobbying to argue that the service should be retained. The visible rise in numbers of people requesting support, in conjunction with the additional strain resulting from job losses, impact on income, housing insecurity and consequential stress and depression put more pressure onto unpaid carers. As previously mentioned, data to evidence whether the loss of the service has resulted in the breakdown of caring situations has not been accessible, but anecdotally the impact was felt by carers:

> "The biggest thing for me during lockdown was when Rethink went, because we were supported by a worker who would ring me every week. It could be up to an hour depending on how I was feeling … we would just talk, and she would listen, and they done away with that service, and they expected the Carers Centre to pick that up, but they don't have the people, or the facilities, to do that."

Some organisations felt decisions regarding cessation of specialist services and transferal of support to a generalist provider was itself problematic, as the commissioning role does not require a specialist knowledge or understanding of, for example, MH needs.

The decommissioning of respite services previously provided through Age UKEL (the Carers Relief Service or CRS) and Apasen in peoples own homes shifted delivery to an extension of individual care packages, with the aim of reducing the number of people going into an individual's home. However, several carers felt the level of experience required to deliver a specialist support service for carers needed comprehensive knowledge of a wide variety of conditions which is not easily replicated through a more task orientated general home care provider. As a carer previously in receipt of the flexi-CRS service shared:

Specialist vs Generalist support

> "The Age UK EL CRS used to be brilliant… I would read a book or go out… we used to book the sitting service and it meant like, Friday afternoon, I could plan to go out and have coffee with a mate, because there was somebody reliable, age appropriate, who knew about dementia, it was a really good service. I don't know what this new service is providing … I can't understand why they've got this contract to be honest".

Communication between care agencies and informal carers was also reported as problematic on occasion, and this was worse during the pandemic when offices were closed:

> "When a person has domiciliary care and the paid carers don't come on time or they're late, or they don't come at all, then whose responsibility is it to call the care agency to say staff haven't arrived or they've missed the schedule? Is it up to the informal stressed carer? That's if they are competent to do so - what if their English is not all that good?"

Changes to the delivery of day care was seen by many carers as increasing the pressure they experience, and there was a feeling amongst some that the pandemic had provided an opportunity for cuts to be made using the argument that carers had often manged without day care provision during lockdown, as voiced by these carers:

> "I don't know, this might sound cynical, but it feels like the pandemic has allowed a lot of the support to be reduced, 'you've been able to cope, you don't need this, you don't need that', and for the support plan and your budget to be dropped."

> "I can't tell you how awful…. it's been just terrible. The fact that we have just aboutmanaged to keep it together feels like we are almost being punished now because people are saying, "Oh, well, you've managed for the last 16 months, so you'll be all right!" I don't know if they really are recognising that people are reaching the end of their tether because they haven't had day care, or they haven't had regular respite,

Specialist vs Generalist support

…or they've only accessed emergency respite and I feel there's going to be more of a need for this than ever before…"

A useful exercise would have been to access and analyse data on admission of either carer or cared for who previously received specialist support or day care to evaluate whether the resources required to support people where a caring situation breaks down are more costly than the investment in more preventative specialist services. As previously stated, this data was not available at the point of writing, but the need for a joined-up approach to support and a whole systems evaluation of pressure points when looking at costs of care interventions were highlighted through a survey undertaken by Carers UK who provided evidence to support how a change in one part of the system can overburden another

Promoting self-help

All operational teams within the council offer a carer's assessment to informal carers in line with the requirements of statute laid out in the Care Act 2014, and if there are identified needs for support, then a carer's support plan will be completed, and those needs then addressed through a range of provision. This could be services directly provided to the carer themselves or those primarily aimed at supporting the service user to enable the carer to have a break. Tier 1 eligibility could include Advice and Information, or if eligible for support, could include respite-type services (Tier 3) In Tower Hamlets there is also a Tier 2 level of support comprising a one-off payment of up to £250 for carers who do not meet the Care Act eligibility, but would benefit from low level support to enable them to continue in their caring role.

Assessments are completed by trained staff at the Carers Centre in acknowledgement that not all carers wish to be in direct contact with the Council. CCTH is the key strategic community asset and many of the CCTH workforce have long established relationships of trust with the carers. There was a recent review of the Carers Assessment undertaken in partnership with carers to ensure that the questions being asked reflect the key things that carers want to share as part of their story.

Scarcity of resources means that apart from adhering to the belief that a flexible support arrangement is preferable for both cared for and carer, the strategy going forward is to empower and enable carers to draw on their own informal networks of support as the default position, much as has been described above. However, many carers believe that they will only be able to access support from services in a crisis, with the assumption being that support is only available in times of desperate need being borne out. The Carers Commissioner explained the policy in more detail:

> "Our work with the Carers Centre is to support carers to prevent/reduce crisis situations and if one was to occur, to ask what the support network looks like to help carers manage and navigate through any crisis. We also encourage carers to complete an emergency plan to help them record the cared for needs but also who can step in. If a carer doesn't have anyone that can step in, then ASC is aware they will need to provide replacement care.

Promoting self-help

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>
> We do encourage carers to consider whether they have familiar friends or family that could support the cared to enable the carer to attend an activity or treatment, as we’re thinking about longer-term sustainability, but also enabling and empowering the carer to have the confidence to ask somebody else to come in and support them…. a lot of the time, it’s around the carer having that confidence to ask for help and recognise their support network is a lot bigger than just themselves as is often the case.”

While it is true that many carers may have friends or family, that does not in itself mean that support may be forthcoming, appropriate, or trusted. The move towards recognising the informal care and support network within family and friendship units could present a potential risk in that not all friends and family members have the skills, level of patience or aptitude required to support a person with complex needs. While the need to ensure allocation of resources is managed well means that the support available to those with no or few informal support networks must take priority over those with many alternative options, some form of risk assessment may be essential.

There is also an expectation that carers will be clear about when the support is needed and to be able to anticipate and voice the potential impact of failing to obtain support:

Promoting self-help

"We're expecting the carer to be able to explain to the social worker that if they cannot attend a chiropractor appointment, they may not be able to do the moving and handling required, and that this may have a knock-on impact on the caring situation."

However, the value of providing ongoing low level supportive interventions through care packages was felt by some carers to be underestimated by Social Services, and the risk of crises occurring on a regular basis heightened if carers were unable to secure regular breaks using informal networks, as this carer explained:

"It got to the point where I had to ring the learning disability team and say to them, if they didn't take him in respite immediately, they'd have to book me into care.''

The importance of having positive and honest face to face conversations between assessors and carers is identified in the Care Act as being crucial to the success of providing appropriate support and promoting a partnership approach to challenge the reliance on overstretched local authority services. As the Commissioner explained:

"We promote the idea of looking within a carers own network, and own community, then to the voluntary sector, and only then looking at what the council can offer…. being able to balance that need around about how much people and communities can start doing for themselves, with how much the council need to start doing for people".

Promoting self-help

An element of this strategy involves agreeing an emergency plan to be held by Adult Social Care, so that in the event of an unplanned absence of the carer, there is a timely way of ensuring alternative support can be provided. The focus on having honest and open conversations about costs of care and giving individuals more choice and responsibility about how they spend their allocated funds has, evidence suggests, successfully changed many of the conversations. In the view of Commissioning, if conversations about scarcity of resources aren't happening, it can become difficult to introduce ways of approaching a shift towards enabling and away from providing.

The current focus embedded in the Care Act around outcomes based commissioning, and how to balance the need to commission and provide services for people that meet their long term needs does not always sit comfortably with traditional social work practice, as many would have been trained to offer a relatively passive model of support and may be less used to talking about both the carer and the cared for achieving measured outcomes, or even considering more actively what goals the cared for may want to achieve in their own right. These conversations can take longer than those taking a more prescriptive approach, and overstretched practitioners may feel they lack the time necessary to engage in this way. There is however recognition of such challenges:

> "We're so used to doing things for people that we're not always enabling those conversations to evolve … we need to ask whether receipt of three hours a week of support can demonstrate that an outcome is being achieved. Clearly, there are some people who will have limited outcomes because of their own health conditions, but some are able to achieve goals through more rehabilitative approaches … This does require quite labour-intensive input however … unfortunately a script doesn't yet exist to ensure that this approach is universally adopted."

Staff morale was also flagged as an important issue, as the reduction in resources available when combined with the impact of the pandemic on the workforce were seen as further contributing to challenging working conditions.

Promoting self-help

“It has been brutal and relentless for many staff, and this is impacting on the numbers of people remaining or coming into the health and social care field.”

The creation of the Carers Academy coproduced with carers was recognised as one of the recent positive developments and another has been the allocation of most carers assessments to the Carers Centre. To enable this to run as smoothly as possible, there are developments underway to give CCTH access to Mosaic, the LA case management system.

“Previously CCTH completed the same carers assessments on paper and then sent them to Social Work, so we wanted to recognise their skills and give shared access. We also know that some people would prefer to deal with CCTH than the LA, and sharing access means we can reach out to more carers.”

There is also recognition that people need information and advice on a wide variety of issues, such as housing, managing stress and maximising income, and CCTH have been highly effective in mapping out and meeting support needs based on a whole conversation, as their skills in undertaking carer assessments is based around the holistic needs of the carer, meaning trust is perhaps more easily established. However, the delay between the CCTH undertaking carer assessments and the Social Care team responding to identified needs has threatened the trust established, with anger, frustration and despair directed at CCTH, in part because their staff are more accessible.

“They tell you to have a carers assessment and then it takes as long as 4 or 5 months until you can actually get some support.’’

In November 2018, 5,000 people were claiming carers allowance in TH, so clearly those people did identify as carers, however not all of them were being supported by the Carers Centre as at that point CCTH identified provision of support to in the region of 4,500 people. This suggests that a proportion of people identify as carers but choose not to come forward for support for a variety of reasons.

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Promoting self-help

> "The data shows these people know they're carers, they recognise the term carers and they're getting their allowance, but then we also know that there are unknown, unpaid carers who won't engage. In our experience it takes two years on average before a carer recognises themselves as such."

The experience of some carers demonstrates the sheer magnitude of the task they face and the need for adequate tailored support and intervention. In some cases, it is clear that the support needed is unlikely to be feasible, as the costs of providing intensive services within the home are likely to exceed that of placing the person in care. Despite the pressures, many carers would not contemplate giving up their caring roles:

> "I have three sons who all have a learning disability and are severely autistic. We are both suffering quite a lot as it's just myself and my wife caring for them – feeding, clothing, washing, everything. When they're at school, we get some free time so we can clean and go shopping, but it was hard when the schools closed. They also prefer to eat some things rather than others. This is how we are living … they're all difficult but the youngest one dribbles all the time and gets his clothes wet or spits on the television and walls … It's smelly and unhygienic so I'm constantly cleaning or changing him… we never get time to rest as we must clean up after their mess constantly…"

To access support, carers need to be aware of how to navigate the system, and the development of the online carers portal aims to quickly direct carers to the most appropriate information and resources to suit their situation. For example, there is a section on caring for someone with learning disabilities and another on dementia which lists local condition specific support groups and events that will be easy to navigate for carers and other sections target carers looking after people with a range of conditions

Carer mental health and wellbeing

ELFT have recently reviewed their existing carers strategy to include more detail in terms of what actions will be implemented and what carers can expect from the organisation. A draft plan has been devised and the main areas are summarised below (link to the full draft strategy is in the Appendices section at the end of the review):Aim to acknowledge and respect that people's needs as carers are recognised and met. Strategy co-produced by Carers, Staff, People Participation, Carers Leads and ELFT.

Five key priority areas are to improve identification and recognition of carers, to ensure staff are aware of carers and trained to engage with them effectively, that there are clear pathways to access support for carers and help in a crisis, ensuring carer voice is considered and promoting involvement (referencing carers assessment, collaborative team approach, co-production) and ensuring that the right support is in place for young carers.

The delivery of the strategy will be overseen by the Carers Strategy Implementation Group chaired by Directors of Social Work, established and meets monthly to oversee and support trust wide implementation of the strategy and local delivery plans, and all ELFT directorates will develop 'Carers Strategy Delivery Plan' that sets out how they will address the 5 priority areas outlined above. As part of the delivery plan the strategy states that ELFT will provide access to co-produced, co-delivered carer aware and young carer aware training in 2022, support for the directorates in the form of central accessible information for carers available in a variety of formats and updated regularly, links to local authority carers services and an annual Carers Survey.

The success of the strategy implementation will be measured through regular reporting from the Directorates, participation and feedback from the Annual Carers Survey, feedback via PALS and complaints, the People Participation Leads and Carers Groups, and undertaking of regular audits.

Psychological Therapies

The psychology and psychotherapies lead for TH for adult mental health services oversees all psychological therapies provision in the borough in addition to being one of two Family Carers Leads for the borough alongside a dedicated carer support worker.

"I've taken on the lead role as it's something I'm interested in, but also because I'm a family therapist as well as a psychologist, so I've always thought that working with families as well as the person who is the identified patient is something that's really important".

Together with the carer support worker, the lead chairs the family interventions strategy group; pulling together a group of professionals, ELFT carers, and third sector partners. Along with the Carers Centre, this group look at how best to coproduce initiatives to support carers of people with mental health problems in the borough.

"One of the really positive things that's come out of the group is much better links with the Carers Centre. In addition to ensuring that all the people being supported by Rethink were referred to the Carers Centre, we also coproduced an initiative to support people who are carers for patients having hospital admissions and in-patient psychiatric admissions".

Another initiative involved one of the ELFT arts therapists providing a dance and movement group for carers at the Carers Centre, which was well received. Many carers shared that their mental health had suffered during lockdown, and another ELFT service called Talking Therapies (TT) have been swift to offer help. The TT Lead reported a rise in the number of referrals during the pandemic but pointed out that it would not always be possible to identify whether someone requesting support was a carer, as the initial referral would focus on whatever difficulty was being experienced, although the role of carer would be taken into consideration at the point of a full assessment.

Psychological Therapies

This results in challenges in ascertaining whether there has been a rise in the number of carers seeking support and tracking any future spikes in demand as well as monitoring success of interventions elsewhere across the system unless such data is recorded.

TT also enjoy a positive relationship with CCTH, and are confident that the staff at CCTH are aware of relevant pathways should they encounter a carer in crisis. TT lead has taken a pro-active approach to their support for carers:

> “I go in once a month to the Carers Centre and run a workshop on mental health, so in terms of crisis support, that is covered within my presentation and there is the opportunity for questions, plus CCTH staff can signpost carers on”.

When talking with carers, it is evident that many feel a sense of duty in relation to their caring role, which, alongside a belief that they would be letting down their loved one or going against stated wishes if they must give up the role, mean such feelings can compete to make it very difficult for carers to admit they are struggling and to seek support. This fear of ‘failing’ as a carer is perceived as reflecting badly on them, or could send a message to the cared for that they don’t love them enough. This can result in emotional support not being sought until a crisis point. As with the Children’s safeguarding team, as previously mentioned, carer specific data is not currently available to support or refute whether timeliness of intervention is key to avoiding a crisis, but the TTL has agreed to ask for a breakdown per month from the ELFT Business intelligence Unit (BIU) of how many people referred to TT are logged as carers going forward.

> “It would be helpful to see whether since Rethink has shut down, for example, this has impacted on or led to any increases in incidences of referral”.

Psychological Therapies

The demands of caring can prevent people from attending the TTL sessions at CCTH, and mapping numbers of carers attending for an assessment and signposting on, as well as recording how many carers can attend assessment and stay in treatment while managing their caring role will also improve understanding of need and enable capacity building to address unmet need. The TT sessions enable carers to spend time sharing their feelings and are led by carers to an extent, with the opportunity to comment on what is and is not working so well in terms of services. Providing the sessions are pre planned and advertised well in advance to enable arrangements for support to be put in place, carers can get their voices heard, although those lacking in confidence may find it harder to speak out. As the TT Lead shared:

> "I saw in my last session that carers are definitely feeling that it's a really hard time, and the group I spoke to were very keen for changes, but they just don't know where best to voice their concerns".

The wait for Talking Therapies assessment is within two weeks from the initial referral, and this contact takes the form of a telephone assessment. A two-week response has always been the guidance, as this time period gives carers a signal that the service aims to see them as soon as possible, and they may be offered some form of interim support until treatment commences. The assessment establishes their suitability for the various support options available and carers will be signposted for appropriate treatment based on the assessment, and their stated goals.

> "A first option may be to offer groups because this helps with management of demand and capacity while providing a timely response. Seeing people in groups is the priority now, otherwise, we have one to one, face to face and telephone support, online support, and the groups, and while waiting to access treatment we also have wellbeing workshops".

Psychological Therapies

Where people feel able to wait for treatment, these wellbeing courses can provide support in the form of a toolkit, such as to carers presenting with issues such as struggling to sleep, or manage anxiety, and those with digital access will be able to attend the online workshops. These workshops are separate from those provided through the Recovery College, and were developed during the pandemic when there was a spike in demand:

> "If a carer wanted to attend the live sessions but couldn't because of their caring duties, we provide recordings as well which we can send out, so we've tried to make it as accessible to carers as possible."

Where the degree of difficulty being experienced by a person leads TT to feel they need more immediate help, they would be signposted away from TT, which is defined more as short term support, towards the most appropriate pathway and services.

> "Even if we were to prioritise them and see them once a week, that's not enough to manage a crisis need, so we would signpost to the crisis services. If somebody is at risk of harming themselves and it's immediate, and we've assessed it then we refer on to the most appropriate team."

Psychological Therapies

Some carers felt that a lack of joined up working between physical and mental health service providers were creating an unsafe environment for those being cared for with Mental Health issues who become physically unwell:

> "It's a big problem with physical health and MH; they do not work together. My friend who is in hospital now had had a bad fall indoors. …ended up with a kidney infection. I went there to visit and he's totally paranoid by this stage. I've got a nurse telling me he's going to be discharged over the weekend, so I said, 'what's the care package'? 'Oh, we thought you could do the care' I said 'No I can't do it … I'm somebody that supports him as best I can in between caring for my son. And I said, 'have you checked with the mental health team what's going to happen?'' and she said, 'what do you mean?' I said, 'he's a paranoid schizophrenic'! 'Oh …. we have to get in touch with the MH team?' Now they are trying to find him a long stay bed in some sort of supported housing and how long that's going to take I haven't got a clue."

Carers experiencing a crisis with their own mental health issues can face further challenges where, as previously touched on, being responsible for another person can potentially compound feelings of hopelessness around not wishing to be seen as 'failing' in their role as carer, so they may find it harder to admit they are struggling and seek support. This could support the argument for provision of an increase in earlier smaller interventions before people reach crisis point, but carers often feel they are unlikely to be able to access such breaks, and many who had sought early help were seen as a lower priority for services than those already in crisis, as the TT Lead shared:

> "Those who are struggling but seen as managing OK will hit the wall if they don't get any kind of regular support. One of the frustrations is, while there's loads of different bits and bobs available, all the services need to connect to see where there's a gap, so everyone can work together to avoid a crisis."

Psychological Therapies

The suggestion that all carers be linked into all the resources available as early as possible was see as vital by most people supporting carers, and one of the frustrations expressed was the perception of inequality of access:

> "Some people know about this service, or they know about another one, but no-one seems to know the full picture. I think it would be worth having a road map where people can see where and what all the services on offer are …"

A process map, created by those involved in delivering care in partnership with those with lived experience would help understanding of how services and support available can fit together, and clarify where the gaps in services or support exist, so that it is not just a picture of what is out there but whether the timeliness of the offer is working for people. Discussion of this model was previously made possible through the THT money which led to regular workshops being held to bring together strategists, managers, front line staff, and organisations from across the system to map services, identify gaps in need and problem solve together.

While ELFT offer specific support around suicide prevention, as well as support for people with a MH diagnosis it is perhaps understandable that in a time of scarce resources, there is a desire to avoid duplication of services. The current and ongoing work being undertaken by ELFT aims to address such issues, and the strengthened partnership between CCTH and ELFT should ensure that referrals for carers will be met with timely and appropriate responses to facilitate the right support at the right time. As the CCTH Chief Executive explained:

> "Rather than being bound by the system, I want to make sure that CCTH are intelligently signposting people and making referrals rather than just giving carers a phone number; actually making the introduction, by phone or physically, to make sure that person, when they speak to the people at ELFT or wherever they're being referred to, that their story is known to them, so they don't have to keep going over it again."

Involving informal carers in the commissioning process

The Chair of the Carers Strategy Group for ELFT has been keen to engage with carers and as previously referred to, commissioned a piece of work across all ELFT services to review support for informal Carers, including those with a mental health need requiring additional support to prevent themselves and/or their loved ones from entering a crisis. In summer 2020 the Equalities Workstream at ELFT carried out a survey to invite informal carers in receipt of their services to feedback on their experiences under lockdown. In November 2020 the findings of the survey was presented to the ELFT Service Delivery Board, and the Carers Reference Group was convened to enable local Carers to help shape service development. A more detailed piece of local mapping of support services followed, and carers group met regularly with occasional additional focus groups being held to ensure local carers were involved in exploring the vision for the ELFT Carers Strategy. (The link to this draft document can be found in the Appendices at the end of this review).

The ELFT Psychology and Psychotherapies Lead for TH adult mental health services raised the general issue regarding working with carers that while clinicians might aspire to work in a particular way with carers, like many other practitioners, they find themselves hampered by various constraints:

> "I think it boils down to the fact that carers, unless they have their own diagnosed mental health problem, are not our patients, so anything that we do to support them is an added extra and not something that we are funded or commissioned to do, and so far our services are set up in a way that expects us to focus on the patients".

There is recognition that this approach can be short sighted given that carers are often key to providing support to patients; and a failure to support carers in their role can mean more reliance on the NHS, which in turn can contribute to the system being avoidably overwhelmed. ELFT recognises that it is in everyone's interests to be working with and supporting carers and while most clinicians participating in the review feel this way, the system isn't always set up in a way that allows this.

Involving informal carers in the commissioning process

> “Clinicians sometimes find it difficult not to tie themselves up in knots worrying about patient confidentiality. If a patient doesn’t want their family involved, then that’s their right, but if a carer is in a position where they are put at risk by the patient, then it seems foolish not to engage with the carer. If the patient has said that you cannot involve their relative or carer, there is still a way of engaging them while respecting this. However, staff are not always aware of this, and may think patient confidentiality prevents all engagement… but you can always listen to what carers are telling you, give support and signposting and offer general advice”.

Examples shared to address the issue of carers feeling excluded include running a carers support group in a community mental health team, which does not breach issues of confidentiality. Similarly, providing carer information about general support available rather than about a specific patient’s treatment, diagnosis or medication is also an approach where confidentiality would be adhered to while enabling the carer to feel less excluded.

> “Carers are not usually asking for specific information, in my experience, but rather for support for themselves, because they’re feeling stressed or anxious, and some general information about what psychosis is and what it means to have psychosis is not secret or confidential. If a carer did their own research, they could find that out, but it’s helpful to be told by a mental health professional: what it means to have psychosis, what you can expect, what the symptoms usually are, and what happens in terms of support available”.

Societal attitudes towards mental health generally can mean that carers internalise what is happening and assume some responsibility for their loved one’s condition, so accessing psychological support for themselves may be an issue. One of the roles of a carers support group might be for carers in similar situations to support each other, and this was one of the recommendations in a recent BPS document co-authored by one of the TH psychologists.

Involving informal carers in the commissioning process

Resource issues and staffing levels contribute to the challenges of implementation of the recommendations, but as previously stated, priority is given to looking after the patient and unless a carer develops their own diagnosed mental health problem, then they are not ELFT's main responsibility. An interview undertaken with a carer of a person with psychosis confirmed this, as they felt they only received support from the Carers Centre, as while MH services were rightly perceived as being focused mainly on the patient.

> "I think if we worked with carers to provide low-level support, they may not go on to develop anxiety and depression, and this can prevent their needing more intensive interaction, but we're not very good at doing that in an upstream way. In terms of MH services, a lot of what is in the BPS document about family intervention and family support is not routinely offered in TH. While we've got quite a big comprehensive psychological therapy service: we don't have anyone employed specifically to work with families and carers."

One key ELFT post which works with the different community MH teams to support them in setting up structures such as carers support groups is the Early Intervention and Family Support (EIFS) role. The patient need not be present when the EIFS meets with the family members if they choose not to, and the service provides specific support to people who have a first episode of psychosis. All research and NICE guidelines emphasise the importance of family work, and the benefits of facilitating opportunities for family engagement. An inclusive approach enables all the family work together and evidence suggests that such early intervention is successful in preventing future episodes and so provides both clinically effective treatment and cost-effective support.

> "I offer a series of sessions to explore communication styles, problem solving, key things that are needed for a family to function well. It's very much about galvanising and building on existing skill sets. Exploring the early warning signs,...

Involving informal carers in the commissioning process

I think, is perhaps the most beneficial aspect to many of our families, and when they come into the service, where previously it's felt like everything's gone wrong, or the world has turned upside down we offer a lifeline. Sometimes it's taken months to get the help they need because sadly, unless the patient acknowledges they have an illness, then it can be impossible to access support".

An opportunity to provide a space for discussion around often complex family relationships, and the dynamics within the household can provide each family member with insights and understanding that in turn support the patient. Having a first diagnosis ofpsychosis is not always through a hospital admission, and assessment can take place through the community mental health teams and sometimes directly via the GP. Current pressures on GPs, where they are seeing more patients than ever before, may sometimes impact on their ability to recognise psychosis, although the main barrier to accessing support tends to be where families will phone the GP, requesting urgent help but the person themselves isn't willing to accept help.

"Unless that person does something awful to themselves or others, not even a GP will Intervene. It's a very difficult situation for many of our service users' families because they're stuck. Our age range is quite vast so you've got some people who are 18 and in some sense that is easier because they're still at school or college with a network around to help them seek that support. But then you've got other people who are working and have mortgages, and things. They're not living with their parents but are now having to call on them for help while at the same time not acknowledging that they have needs that they didn't have before".

It can therefore be frustrating for the carer or any people around the patient who are aware of the situation unravelling while being at a loss as to where and how to seek help. The EIFS integral to the setting up of monthly carer support meetings, and while attended regularly by a few carers, the challenge remains around delays to accessing support.

Involving informal carers in the commissioning process

"Many carers feel frustrated about access to timely help and we are planning an event open to all our carers to enable them find out a bit more about psychosis and signposting. One coproduced idea was doing regular rolling programmes of information sharing at places like Ideas Stores and GPs surgeries, but again it's about funding and manpower to do it".

These ideas may not come to fruition while there is only one EIFS worker in post, as this would inevitably take time away from consultations with patients, so this approach around widening knowledge of psychosis needs to be whole systems to enable greater awareness of the importance of timeliness of the recognition of symptoms and need for support.

"The big thing is awareness of what is normal and what is not. Families struggle with that because we all have complex family situations whereby you may only see someone occasionally, so it can be hard to negotiate what is or isn't OK or acceptable. I think families often come to us because they want answers around what they did wrong! Often, it's not something they did but rather an accumulation and combination of many little things, be it stress, drugs, society, or Covid, or even climate change anxiety. Some people are a bit more vulnerable to reacting in a psychotic way".

An observation made by the EIFS worker was that men tend to come straight into intensive care as they suffer more severe psychotic episodes and seek support and help at this point. This points to a need to consider what steps or interventions could be available before they reach crisis point and how can communities be educated to pick up on the signs and raise awareness of the pathways available to support people.

"Sometimes it's not just about getting the help straight away but having a record thatyou sought help and notifying people that need to know that this is going on. Personally I've offered family work to under 18s, like siblings or children because I think it's so important for their voice to be heard and also because they're probably anxious about whether it may happen to them too. I'm trying to provide that reassurance, and guidance around self-care, eating and sleeping well, and signposting to the people who can provide support if needed".

Involving informal carers in the commissioning process

There are some useful local voluntary sector services for young people such as Step Forward which provide counselling and support for carers, or those suffering their own emotional or mental trauma, although such organisations tend to have a long waiting list. The EIFS is seeing very positive outcomes anecdotally, but along with other preventative interventions, data collection is still a work in progress. The post was only created in March 2021 and a caseload was not held until June 2021, so it is early days in terms of outcome measurement.

> "By background I am an OT and have worked with the ELFT since 2005. I've always done family work, but not in such a boundaries and guided way; before I was doing it in addition to my care co-ordinator role, whereas now it's all family work. It's amazing, I love it because I feel families have always been the key to making the change. I know one of the people I've been working with has returned to hospital, but I think that's more the nature of their illness. Others have all stayed out of hospital … I'm keen to work on developing the data and understanding what's going on, as well as pushing for it to be part of our everyday practice. I think that often data is deprioritised because everything else feels so pressing".

Given that the responsibility of ELFT is the patient and not the carer it is unsurprising that carers and family members may feel excluded and may lack the tools to equip themselves to deal with a crisis or a pre-crisis, or recognise the signs at which point they need to support the person to have an intervention. EIFS have been encouraging co-produced 'staying well'plans, and this may entail two versions: one for the service user and one that they feel happy to share with their loved ones.

> "Obviously some of the young people don't want to put down, "I was smoking cannabis!" So they don't need to include all that information. There's the importance of encouraging family involvement, but also leaving the individual the autonomy to make decisions about what is shared".

Involving informal carers in the commissioning process

WhatsApp groups have proved very useful in keeping carers involved and informed, and it has been useful in containing an easily accessible copy of the staying well plan and including contact names and roles of those who can be contacted should help be required.

The EIFS adopt a fairly flexible approach to eligibility criteria as sometimes people may have experienced symptoms for many years but never accessed any treatment, so can be accepted as having a first episode because they have not had an effective intervention. The team can be involved with an individual for three years maximum in line with the NICE guidelines around early intervention services.

> "It's very much about saying 'You're with us for three years, how do you want to use us? What do you want to work on? Where can we come in? It's very much focused on prevention, 'What can you do next time; let's hope it doesn't happen again, but if it does, how can we help prepare you and help you navigate the system?' "

The majority of people are having fewer spikes in crisis and more stability and the EIFS feels this in part is due to time invested in educating carers to help them understand psychosis and the reasons behind the behaviour displayed.

> "Each team needs to have an allocated specialist who leads on the family work. A sole post dedicated to family support … this would mean there was more opportunity for resuming the sessions I used to hold on mental illness awareness training but also to offer more specific information on prevention and what services are out there. This could be in Ideas Stores as a drop in, and also sessions in GP surgeries, and not just for the GPs because admin staff seem to be involved in triaging phone calls, so would benefit from MH education"

Involving informal carers in the commissioning process

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Community Education Provider Network (CEPN) could potentially work in partnership with ELFT on delivery of such training, and social prescribers could also be invited to engage, as they may encounter opportunities for early intervention where GPs would find it challenging to spend time 1:1 unless somebody is clearly in crisis. Skilling up as wide a group as possible could enable and optimise more opportunities for early intervention across the system. Roles such as Social Prescribing is likely to be a first point of contact for families and carers, because if they feel overwhelmed, this may trigger a visit to the GP surgery.

Alongside being the first point of contact, the need for an up-to-date well-managed portal as been recognised by many of the professionals who participated in the review, and as described earlier, is being overseen by the LA and led by the Carers Commissioner. ELFT stressed the importance of family intervention/family support to be more generally available, and pointed to a strong evidence base in psychology literature about the efficacy of the role and the way it prevents service users having relapses, being readmitted to hospital and prevention of carers experiencing burn-out and developing their own mental health problems.

> "That's something that MH services should be offering; it shouldn't just be optional extra, it should be a core part of what we do".

Involving Carers

The LA Commissioner for Carers services is also committed to involving carers in service design and co-produced the last Carers Service strategy, as well as co-producing the new service due in 18 months' time, with the consultation and involvement process beginning this autumn.

Although part of the carers strategy previously included a range of outreach services and satellite bases to enable CCTH to reach all parts of the borough, the pandemic has impacted on these plans, and while is hoped that outreach services may in future be hosted by several organisations, including GPs (who are seen as having a key role in identifying potential stress in informal carers), there will be a joint approach to signposting for support through social prescribers. The Carers Commissioner talked about using every opportunity, such as training events, to get staff to think about carers needs, and the updated EMIS system enables referrals to be made directly to the Carers Centre.

Thus, a GP can refer directly to the CCTH who can then follow up, eradicating the need for the carer to present themselves, and so enabling the system to work around the needs of the person rather than the carer having to navigate the system. The emphasis on the Carers Centre as the central point of access for support for informal carers means that CCTH have had to adopt a flexible and critical approach to ascertain how agile and responsive their services are in being able to meet need. However, the waiting time for Social Care to action support identified through a Carers Assessment is very lengthy in some localities, and this presents a real challenge for CCTH.

As part of the Carers Centre remit, respite can also be facilitated for LD and day services as well as for those caring for people with severe and complex needs, with individual arrangements dependant on the agreed care and support plan, but the pandemic resulted in limitations on available respite, and this according to CCTH insights, led to some people nearing crisis point, so, as illustrated in the section looking at day care for those with dementia, there is potential learning from examples of creative responses implemented their success in preventing potential breakdown of the caring situation.

Involving Carers

“For some carers, due to the pandemic respite didn’t happen, but the LA commission the London Buddhist Centre (LBC) in partnership with CCTH to enable 60 carers to attend overnight retreats, with the focus around access to peers, but also supporting individual mental health and wellbeing. There is also funding to enable the carer to go away with the cared for, because the pandemic has forced people to be closer together during lockdown, in recognition of this, and the possibility of guilt or separation anxiety, we created opportunities for carers to decide whether they wish to go away with the cared for person or by themselves, with other people.”

The current expectation is however that if a carer attends a retreat, they need to set up an arrangement from within their own support network to ensure care is provided for the person they normally look after, which as previously described may prove a challenge to some carers. Unless the cared for person has very complex needs, or the carer feels at crisis point, routine respite is expected to be provided by informal networks, with Adult Social Services only providing support in emergencies. The LA is looking to develop flexible and easily accessible services to step in at short notice to meet respite need:

“Home care services are not always easily accessible without an assessment or care and support plan, and that can take anything up to 13 weeks at the moment, so we need to develop a flexi-service approach.”

It is assumed that all social workers will have a high level of carer awareness within their role, and in addition there are Carer Champions in every Adult Social Care team who are able to keep abreast of any new service updates and developments and it is expected that they will share this perspective within their local teams including community mental health and hospital social work teams.

Life Course Workstreams

Carers support initiatives do not appear to feature directly within any of the Life Course Workstreams, although carers issues are likely to be of relevance across all workstreams. Instead, the workstreams adhere to the commitments outlined in the published carers plan. Pre-pandemic, there was an intention to roll out a toolkit to enable partners across THT to identify new or unknown carers, as well as enable organisations to reflect on how carer aware individual teams might be, as the Carers Commissioner explained:

> "We planned a tiered structure where teams could evaluate their carer sensitivity by level and address any shortcomings in awareness or support by using the toolkit as a benchmark, however a lot of this work was delayed because of the pandemic."

There is a realistic approach to managing expectations amongst carers in terms of support that can be provided in a sustainable way. While the LA will and can provide support in the short term, there are concerns about creating unrealistic expectations about provision of longer-term support in the community due to lack of resources. Along with partner providers across THT, the need to acknowledge and counter the established culture of dependency and instead promote adoption of an enabling approach is seen as key to shifting and managing expectations. One area where this is being explored in a creative way is support for former carers, as current carers are by necessity the focus of existing LA resources:

> "We are identifying funding to enable former carers to support each other and transition into achieving employment or active independent lives, so we support them to access grants… to address their support needs and listen to their ideas around how to adjust to life beyond caring. We are empowering former carers to develop this partnership work, such as help with funding bids, and awareness of highlighting the cost effectiveness of interventions…. as well as support the monitoring process of successful bids".

Life Course Workstreams

The idea of empowering local people to explore a range of options available and take control of decisions about services as members of their communities has the idea of ownership of local resources at its core, and while this approach has the potential to be successful, the structure of local government was identified as a potential barrier to being able to realise this vision:

> "The council's approach to contracts and grants is potentially problematic; there's a subcommittee that will be required to know every single detail, and that doesn't sit well with models of empowerment. Because it's innovative, it's seen as risky."

The LA also identified funds to support Covid and recovery, with a focus on mental health and helping people post lockdown, and this included support for informal carers as well as addressing staff mental health which was acknowledged as requiring input to help integrate people back into work and the community.

Support for Carers of people with dementia

Support provided to this group of carers was, as previously touched on, both creative and exceptional, and this positivity was reflected in discussions with carers themselves. In mid-March of last year, Russia Lane centre, like many others, was closed due to the pandemic, and there followed an immediate response from the centre Manager and staff whereby the service shifted to provision of outreach visits throughout the pandemic.

> “We just knew that carers would need support during lockdown, and this support entailed some experimentation which evolved into more individualised support strategies and solutions over time. At first, we tried to replicate the attendance at the day centre so if attendance had been three days a week, we would try to deliver that at home. Over time it was clear people needed more, so the visits were extended. It aimed to enable carers to just catch their breath, to go out and get some shopping- because remember early on people were unable to get online delivery slots”.

PPE was less of a challenge than it might otherwise have been as the team had the foresight to stockpile resources early on, and over time to access weekly supplies centrally, as well as the council adopting an innovative approach to providing informal carers with PPE, accessed via the Carers Centre. Initially, as was the case more generally, there was some hesitancy about having staff visits at home as conflicting information and lack of clarity about safety from government sent some confusing messages early on.

However, half of the carers of those attending Russia Lane immediately accepted the support offered and the team maintained contact via telephone with those who had refused visits, so gradually more carers began requesting and accepting home-based support. This support took the form of tailored activities and socially distanced outings designed to stimulate those being cared for and prevent loss of orientation and social skills.

Support for Carers of people with dementia

"The team were so creative, and it really depended on the individual and their interests. For some people it was getting the most out of their gardens. One man refurbished his entire fishing pool, and they went fishing around it. We engaged with many of our partners such as the Museum of London, and Alzheimer's Society who did some sessions with us near the end of the third lockdown."

There was acknowledgement of and concern for those who lacked digital access or who were afraid of or reluctant to acquire new skills, and TH provided the Russia Lane team members with laptops within a few months, so enabling them to support people to engage in online facilitated sessions. Not only did this prove beneficial in relation to the work with carers of the Russia Lane attendees, but also supported carer engagement with other providers of support in the borough, including access to online activities or with practical help such as form filling or accessing benefits. However, for those with additional barriers to connectivity, including poverty or challenges around physical abilities, accessing digital support remained a challenge.

There was also a wide range of abilities among attendees at the day centre, with the needs of those at different stages of dementia being catered for, which meant that team members were required in some cases to upskill to enable management of one-to-one care in the context of home visits.

"It was a big change and involved some learning, as it really required staff to have insight into the carers journey, and a lot of the support for the team shifted to our supporting staff to be able to support the carer".

Whereas in the day care context the focus was very much on the individual cared for person, the pandemic necessitated a greater understanding of carer needs in addition to those of the cared for, resulting in more emotional involvement with families and their caring situation. As the manager explained:

"It got to the point where staff had their own mugs in people's homes"!

Support for Carers of people with dementia

There was an awareness of the risk that workers could become incorporated into the caring situation, which posed the danger of staff stress levels rising to a point where they could be akin to that experienced by informal carers, so a strategy used to manage this was to assign three staff to each service user, ensuring that there were opportunities to discuss stressful situations as well as ensuring adequate experienced and familiar cover was available for holidays, training and staff sickness.

> “This approach worked well really well as it’s a very small team of only seven staff. At the beginning of the pandemic there were 24 service users, and although we’ve since taken on new referrals the number went down.... which wasn’t expected. There were quite a few deaths from Covid; both acquired in hospital and in the community, which was hard. From data on carers and service users, it was those with a diagnosis of advanced dementia who didn’t survive Covid”.

As previously discussed, there was a move some time ago to place the two specialist dementia workers employed through Alzheimer’s Society to CCTH to share their skills with the wider team to help raise awareness of dementia and contribute to delivery of more generalist support. This move impacted on carers looking after people with dementia to a degree, in that they may be less up to date with specialist knowledge of developing treatments, but senior LA managers felt a greater impact on carers resulted from changes to the contribution towards care costs, which for some was a factor in decision-making about which services they engaged with.

Respite care outside the home

A senior LA Manager shared that carers were able to access regular respite once more by April 2021, although this was not always straightforward as is reflected in the experience reported by one carer:

> “The day care support hours had been reduced, my son has physical and learning issues and was in a bubble, but didn’t really understand it and wanted to see other people … he was at the centre from 10am until 2pm, so it was a smaller window of respite … to pick him up I had to leave at 1.30pm and even though it’s quite near, there was often traffic … the pressure built up and I got to the point where I asked for urgent respite as I felt it was an emergency …. he went in at 4pm the same day, and then at 7pm they rang to say he’d had a seizure and was in hospital, so I had to go and collect him again after only 3 hours respite… Obviously, the seizure couldn’t have been foreseen, but his anxiety about attending respite after such a long absence, and not knowing staff, could have contributed to it. When I later requested and secured another period of emergency respite, I received a call to say he had fallen and broken his tooth, which took several weeks to get fixed! He hasn’t attended respite since (so it’s now been 12 months) as there was a recommendation to use a pressure mat to alert staff if he gets out of bed, and it has been out of stock so I am awaiting an appointment for an alternative device for respite, and until these safety measures are in place, there can be no safe overnight respite. I don’t think they understand the pressure … you can’t do anything because all the attention is on him, even when he’s sitting down and doing an activity, every 10 minutes he’s calling me over to see what he’s done, or if he needs help, or if he wants to do something else; he’s just constantly wanting reassurance or attention”.

Prior to the roll out of second vaccinations, social workers were supporting the cared for to have Covid tests before going into respite to ensure that breaks were regarded as relatively risk free, but real confidence was in evidence once most 2nd vaccination doses had been received. Managers were able to monitor uptake of respite and had an overview of the situation through insights into operational social work teams as well as day care services, so had both a provider and assessment perspective:

Respite care outside the home

> "I have knowledge of carers support plans so know where funding of respite is happening. Utilising different facilities in the borough for respite care, both for planned regular respite or in an emergency, means if a carer is admitted to hospital, we organise emergency respite in a tailored way to meet the needs of that particular user and carer and their individual circumstances".

This individualised approach can work well as is illustrated by the example of a carer in receipt of direct payments who had agency staff taking up residency in the house for a period of a few days to enable the carer to go away for a break. The care providers were block-booked for the duration, and this worked for the carer as concerns about covid safety were successfully addressed. Where an individual has dementia or complex needs, a familiar environment has been found to offer a better option for consistency, trust and orientation, and a flexible approach to respite delivery such as this provides an appropriate option for carers who may otherwise feel too anxious to enjoy their break.

Inclusivity and provision of support across communities

Sonali Gardens is a local voluntary sector provider that predominantly serves the southeast Asian communities, with most of their staff being bilingual. They provide day care support to people with dementia, but also cater for a wider group of people.If someone from this community develops significant challenges in terms of behaviour linked to their dementia, they are likely to be referred to Russia Lane, as although providing high quality support, Sonali Gardens is not a specialist dementia service.

However, an interview with a member of Sonali Gardens staff suggested that many attendees with dementia and their families prefer their non-specialist service as they can enjoy a culturally sensitive and familiar environment, which is particularly valued where someone may be losing their bilingual abilities, even if there are evident skills gaps among staff where a person develops a more severe form of dementia.

Based in Newham the Alzheimer's Society have a Somali dementia support worker who also covers Tower Hamlets, but despite many attempts, contact was not able to be established in time for inclusion in the review. The LA did, however, facilitate and invite the team to attend a Somali carers group, and this enabled access to this community of carers' experience, and the issues raised were not dissimilar to those of the Bangladeshi community. It may be appropriate to explore options around provision of a Bengali and Somali dementia specialist worker who could work at Sonali Gardens or a trusted community centre welcoming Somali older people with dementia, and this may offer a more practical solution than provision of a service for all communities experiencing cognitive impairment operating from Russia Lane.

Russia Lane also employs a specialist day centre dementia officer who facilitates a carers support group and runs regular sessions for those looking after a person with dementia. As previously discussed in relation to CCTH, carers at Russia Lane also reported having developed or experienced new or worsening mental health issues during lockdown, including disruption to sleep, and general heightening of anxiety levels. Carers felt that lockdown impacted on their wellbeing as they had previously accessed in-person support from friends, family members or voluntary sector agencies.

Reimagining Day Care

The LA has also undertaken a review of day care services since the pandemic, both to examine cost effectiveness during a time of scarce resources, but also to evaluate whether an outmoded model was failing to provide the type of support people really want. This evaluation has resulted in the closure of two in-house day services and released £1 million in savings. The challenge around resources may have acted as a driver to evaluate services, but evidence suggests it has led to a more creative approach to day care provision. However, support provided in other ways such as in the home may result in cost implications for the carers themselves as heating and food costs will fall to them whereas before this would have been covered by the attendance at day care.

Integrated working across organisations was not viewed by most interviewees across THT as having been particularly successful in providing a better way of sharing finite resources but rather was viewed as an additional challenge at a time when most organisations are still reeling from the impact of the pandemic. A short window of more cooperative working across the system was identified by most as being in evidence at the start of the pandemic but was being mourned by several interviewees as now seeming like a distant memory.

> "I still see failed hospital discharges every week… and yet we have been trying to address this for years… only last week I had someone who needed a profiling bed, mattress, commode, incontinence pads, medication, and they were discharged before any of these had been provided!"

There was a sense amongst some carers that the pandemic has on occasion been used as a reason for untimely discharge, where the risks to patients while in hospital were deemed to be higher than a rapid return to the community, and while there are recognised benefits in having an integrated approach to commissioning on the operational side there was seen to be limited improvements in integrated working from a user perspective, and some way still to go before truly integrated systems can be achieved.

Reimagining Day Care

In relation to the impact of day centre closures on informal carers, it might be anticipated that this would potentially have a negative impact on carers, however generalist provision, across in-house and externally commissioned day services has seen high numbers of vacancies for a considerable time, so clearly services were not being fully utilised, and this was due in part to the model being regarded by many as outdated and no longer a viable or desirable option.

“Specialist day care such as Russia Lane clearly does have a place, but some of the other day services have more ambitious outcomes now and need more personalised approaches to support in meeting care needs”.

Just as there has been a move away from the notion of ‘sheltered housing’ towards ‘supported housing’, and similarly with support provision for people with a learning disability, there is a move away from a passive model of care. Russia Lane has been delivering this very active model during lockdown; looking at personal interests and individualising that support and care to ensure active engagement, stimulation and enjoyment from the interaction as well as providing the carer with a much-needed break.

“It became clear that you don’t necessarily need a very expensive building-based service to deliver that kind of approach. One of the day services that closed only had two people attending on one day of the week and yet we had a full staff team there, so that is clearly not the best use of resources. When we know that we have got financial pressures, it is not possible to sustain that type of outmoded model”.

Personal budgets and Health budgets are seen as a more progressive way of providing a tailored approach for people who do have needs and require support with accessing areas of interest, and despite some carer hesitancy around adoption of this alternative provision, it clearly has potential value:

Reimagining Day Care

"Why spend 45 minutes on a bus with a load of people that you have nothing in common with to go and sit in a service that really doesn't quite meet your interests? If you like shopping, you can arrange a support worker to go with you in a cab, go to Westfield, or if you like being outside, go and explore the London parks, go to a museum in central London, go to the theatres…. do something you're interested in…."

Communication

Communication issues between service providers and carers was mentioned more frequently than any other issue, perhaps because of the key role played in enabling carers to access support which requires understanding of their often-complex needs. When good communication is achieved it enables seamless and effective joined up working between services and supports both carers and cared for. Carers have talked about poor communication between health and social care staff and how this has led on occasion to exacerbation of health issues. One carer explained that her mother needed to stop taking one antibiotic and to change to another but facilitating a urine sample before this could be actioned proved difficult:

> "The district nurse said they had not been instructed to take the urine test and I was just wondering what happens sometimes with communication between these services. There doesn't seem to be much flow of information… and it often gets lost, so that's my concern. In the event, paid carers came and took the urine sample".

Other carers talked of difficulties and frustrations in obtaining their Covid vaccinations early in the programme if they needed to change an allocated date due to being a carer while others felt that COVID information did not adequately recognise the role of unpaid carers:

> "They had a sort of 'halfway' recognition of paid carers who reside with the person they look after, but anyone who was an unpaid carer living at another address, that was a different matter …. all the services are aware that mum doesn't have anyone coming at night time, it's mainly me helping out and sometimes my brother, but that side of the role of informal carers who live elsewhere was initially forgotten and nobody even addressed it."

Many carers experienced delays in accessing the vaccine, as they found they were not listed as carers with their GP's, so as previously mentioned, the CCTH Chief Executive took an active role in negotiating and resolving this issue.

Communication

Another carer felt that the specialist support needs of the person they look after was not being recognised when advice was sought, as they were advised to contact the Idea Store to get support when the Day Centre was closed due to the pandemic:

> "There's only so much you can do in an idea store. My son's communication is Makaton sign language, and he's very fit and well and able to go to a gym, and wash himself and feed himself, but communication is the problem. I had to take him with me to facilitate successful communication of his support needs."

Many organisations made a point of pro-actively keeping in touch with carers during lockdown, which was much appreciated, but several carers remarked upon a lack of contact by others and the negative impact this had:

> "I have to say with the Learning Disability team, we've only had the odd meeting. I don't know how many they've got on their books, but they haven't rung carers to say, "How are you coping? Is there anything we can do to help?"

One carer who reached out when in crisis felt that there were some who responded while others clearly lacked the skills necessary to support or reassure them:

> "I believe that in all service-providing organisations there are individuals that go above and beyond their expected supporting role, and in contrast there can be staff within these organisations that really (maybe due to being new to the role or agency staff) who haven't necessarily developed the art of reassuring a carer or have adequate experience or knowledge to pass on to a stressed carer in times of crisis! I believe there are many lessons to learn, which have been highlighted during the pandemic, that when a need has reached crisis point, there is in place an immediate rescue package to support a carer in crisis, in their caring role".

Communication

The Carers Forum was also flagged as not keeping in touch with carers to the extent that some would have liked, although staff members challenged this perception and explained that regular calls were in fact made, although expectations may well have exceeded capacity in terms of frequency or duration of calls.

Several carers reported that it was taking longer for them to receive information and that this had resulted in some confusion, particularly in relation to MH services:

> “They told me my request for support would have to go to brokerage, and I phoned the next morning and spoke to a different member of staff to ask for details as my daughter was discharged with no warning or discussion, and they disputed the fact that she had been discharged … when they realised she had, they told me that shouldn’t have happened … but they never readmitted her, they just left her here with me.”

Housing was an issue that was raised by many carers who felt that there was a lack of appreciation of the vulnerability of some tenants, and a lack of appreciation of the social implications of being in unsuitable accommodation as a carer. As one person commented:

> “One of the things I’ve always advocated is the joining up of health and local authority and housing. They always work on their own as mavericks and independently … for example, Clare House which chucked everyone out due to building safety concerns…there was very short notice given and no awareness of how it would affect vulnerable people”.

Another had experienced a lack of sensitivity in relation to the death of the person for whom they had been caring after being expected to vacate the property unrealistically soon:

> “I lost the cared for person and was told to downsize and move out in three weeks.”

Communication

Carers also criticised what they perceived to be wasteful use of resources in terms of properties with adaptations, with concern voiced about failure to keep a record of the work invested in making properties accessible:

> "I've had lots of adaptions done, like a through-floor lift and it was still down on record that my son had a stair lift instead, which had been put in ten years before the new adaptations. There was no recognition or record of all the work that had been done subsequently, thousands of pounds worth … but nothing on a computer to log it …. there should be records kept by every housing association doing social housing, like a flag to note if a property has a walk-in shower, this property has a ramp, or that property is designed for an elderly person … nobody seems to be keeping stock of what adaptations have been carried out on properties and this is wasteful."

While this is likely to be associated with the need to tailor every adaptation to the specific needs of the individual, it is seen by some carers as wasteful that there is not an up-to-date recording system to enable matching with more basic needs, such as for a walk-in shower, to ensure property is allocated to people with mobility issues.

Several carers described the struggle to get adequate support to enable discharge of the cared for from hospital or their struggle to prevent hospital discharge without this adequate provision being in place:

> "My partner was diagnosed with stage 4 cancer during lockdown and went into hospital…. they tried to discharge him when he was very unwell and not eating or drinking as they said it would be safer as Covid patients were coming onto ward. I was a Social Worker so know the system and I fought my corner …. I also care for my mum…."

> "I went to the doctor as I felt if I didn't get some help I would either have a heart attack or a breakdown because I already had problems with my heart… the doctor got my husband into hospital that night, and he's been in there for some time

Communication

…. otherwise, I couldn’t have coped. They said if he comes home, they will send someone to help him to the bathroom but other than that I would have to stay indoors 24 hours a day … I couldn’t cope with that as I suffer from depression …. they say I can pop out and get some shopping when the carers are there … but once they leave it will all be left to me …so I don’t think I can manage.”

“My husband discharged himself from hospital after being admitted when he had a hypo and fell at home. He had a brain bleed… I was on the phone begging them not to discharge him … where was the social worker when my husband left hospital? … I couldn’t cope and nobody listened. I got him readmitted, but he’s refused the support services …. I feel like no one listens to me”.

This conflict between the need to free up a hospital bed when the person is medically stable and the capacity of a carer to manage a change in the needs of the cared for person is a significant challenge. A reluctance to accept aids and adaptations that may make the task of caring safer and easier is also something that was frequently reported. The carer may feel emotionally unready to accept a deterioration in their loved one, and so be reluctant to accept that the layout of their home may need to change, such as to accommodate a hospital bed, despite this being in the best interests of the patient. More time invested in supporting the carer to adjust to a change in the need would perhaps help enable the caring situation to be sustained, but in a busy hospital environment this may well prove unrealistic.

The AADS and Reablement service were also appreciated by many carers, but the Reablement Officers are perceived by some carers to be under too much pressure to give the required quality of support within the allocated amount of time:

Communication

“The reablement carers just want to be done and out …you have to ask if they give them adequate priority in terms of training and support? It feels like nobody is applying for care work because of the low status of the job…. this is common sense. Covid or budget cuts is no excuse for poor service delivery….”

Another concern raised by carers was around communication with GPs as a starting point to access MH services. There was frustration and a lack of understanding around why GPs were not resuming face to face consultations as often as had been previously accessible:

“I feel GPs are taking the mickey, the fact that you can’t get face to face… I’ve been a carer for a long time … my wife’s a stroke survivor and while she doesn’t require the intensity of support that some people do …we don’t get a lot of support … when we started the caring journey, we got some help around mental health and counselling for my wife… that was very useful…. a very positive thing. I think she needs to access it again but…this is the first year I’ve needed it too… it all got on top of me, being stuck in the house. When I went out to work that was fine, that was almost my respite, being able to travel, be at work and interacting with other people, then maybe having a cheeky pint after work, or travelling on the train reading a book, that all went as like most people I was working from home…. 24/7 in the house”.

CCTH, however, proved a helpful starting point in terms of accessing emotional support that carers could access, as described by carers:

“I reached out to the Carers Centre who were putting on some mindfulness and I found it useful but then I needed something a bit more intense and there was a counsellor at CCTH I saw, and I found that useful for a while. Also, I had respite a couple of days at the Buddhist Centre which helped.”

Communication

> “I took the opportunity to attend the carers retreat at the Buddhist Centres’ Vajrasana (this August) which I found out about from the Carers Centre newsletter. I have also reacquainted with the Carers Centre and have been attending the ‘crafty conversation’ sessions there as well as enjoying the carers meditation sessions at the London Buddhist Centre.”

As previously touched on, access to the longer retreats has also changed with the expectation that friends or family will enable the carer to take up the offer, and while in theory it should be possible for carers to increase an existing care package, this is proving harder to access, so fewer carers are able to attend. As a CCTH advocate explained:

Communication

> “From my perspective as a worker…. even before the pandemic, I was advocating on behalf of a carer on the phone to adult social care, trying to finalise a care package promised within 2 months’ notice of going away, and they were saying it hadn’t been agreed. The carer felt so angry she decided to cancel her trip because the support hadn’t been put in place. This is an age-old thing at the eleventh hour, and they shouldn’t be having to deal with it, still being on the phone with social care asking, ‘are you coming tonight to look after my mum?’. They shouldn’t be having those debates on the day they are going away …”

Best practice in terms of communication was identified by many carers, however, and as previously described, Russia Lane was singled out as a positive example of adopting a creative and much appreciated approach in a time of crisis. The voluntary sector was also lauded for their good communication with carers and in particular for their efforts to contact potentially isolated carers:

> “Sonali Gardens did phone calls to support us and later started going for walks with the cared for people … sometimes the consultant from the Mile End Memory Clinic phoned me up too.”Neighbours in Poplar (NIP) was particularly recognised for their efforts in keeping in regular contact with carers, and for their consistent offers of practical help and support:“Sister Christine is helpful, and her volunteers are so good too…. I belong to NIP, and I must admit they’ve been absolutely marvellous. They’ve been ringing up saying, “Do you want any groceries, do you need anything?”

Other carers acknowledged the support provided by Social Workers, some of whom made regular calls enquiring about support needs and whether there was a need for increased input, although other carers felt they were overdue a review of their changed needs.

The key role of Carers Centre TH (CCTH)

The CCTH Chief Executive shared some of the challenges faced by the organisation during the pandemic, and the need to continually change their approach to ensure informal carers were able to access the support they needed. This need for a flexible approach continued as the increase in issues faced by carers because of lockdown was much in evidence. Many carers shared that the Carers Centre had offered them what they described as 'a lifeline', with the impact of the day centre restrictions and attendance and access to regular respite presenting two of the main concerns to emerge from their annual survey.

"People found it hard to access respite to have some time to themselves, and so felt tired and exhausted. The fact that the person they were caring for was not able to have any time away from the home at all meant that often the carer struggled to go out and do things for themselves, as obviously you can't just leave someone who is high in need, so and a lot of carers reached quite high stress levels."

The informal contact facilitated by CCTH that enabled people to interact with other carers and engage in dialogue and activities that were not centred around being a carer was not available to them while the Carers Centre was closed, neither were hands on wellbeing sessions and relaxation days. A more positive aspect to the pandemic was that some carers reported that caring responsibilities were shared, whereas before it had mainly involved only themselves. As the CCTH Chief Executive explained:

"Only 38% of carers felt they were better able to pursue some of their own interests, and that was linked to being unable to just get out. 43% felt supported to find time for themselves having a break from caring, which may be linked to more people working from home, so being more available to help the usual carer."

The key role of Carers Centre TH (CCTH)

This was particularly evidenced over the summer months of 2020 where carers were able to go outdoors to unwind, safe in the knowledge that someone was WFH so keeping an eye on the person they cared for. However, during winter and the arrival of a less warm and sunny spring and summer of 2021, people were less able to spend time outside. It was also reported that as working from home became less of a novelty and as people settled into different routines, offers of support tended to dwindle as there was a realisation that this was 'the new normal' for many who found themselves with competing demands on their time such as home schooling, so offers of help to carers became less sustainable.

Many carers shared with us just how important CCTH had been in helping them and their elation when the physical building opened as soon as it was safe to do so:

> "The centre was completely closed for a long period. It was much valued as a resource, but when it was shut, we really missed it, they have been really, really helpful ... I mean, they do therapy days and advice…."

> "Before the lockdown I used to go to the Carers Centre. They would have some activities and I would join them … art and massage, and that was lovely. When you're a carer it's just finding the time or you're not in the mood to go out … I did miss that though as I am a people person …"

As part of the Carers Survey carried out in autumn 2020, CCTH asked specific questions relating to the pandemic, namely how people had felt about their mental and physical health, and how their financial situation had fared. There was also a self-assessment scale to evaluate whether their situation had got better / stayed the same or become worse during the pandemic. Interestingly, over half of respondents in all three categories said their situation had stayed the same, while just over a third said it had got worse. In particular, and somewhat surprisingly, carers stated that their physical and mental health had stayed the same (around 52%) as had their financial situation, which was likely to relate to the benefits uplift.

The key role of Carers Centre TH (CCTH)

Over a third of people in all three categories felt things had got worse, and the cessation of the benefits uplift combined with figures relating to delays in accessing non-covid related treatments may have further impacted on carer wellbeing since the survey was circulated for completion. As the Chief Executive of CCTH explained:

> "Where it stayed the same, it is possible people thought that it had been such a strange year it was quite hard to measure wellbeing. Also, people's perceptions of themselves and others changed, so if they did have Covid and their physical health deteriorated, they may not have registered it as they may have felt a lot of other people were in the same situation. And people don't always see those changes either because they can be quite subtle or they could just be incremental over time."

The issue around people perhaps not recognising changes in their health and wellbeing, and possibly only becoming aware of subtle changes when they began being more active and sociable may well have been a factor in the timing of the survey:

> "Sharing personal stories can be useful to carers, particularly if they have had a rough time, but it's also about making sure the services we're offering are meeting need and we can often pick up on how carers are feeling through these stories, and why they've picked our organisation in the first place."

The experience of Young Carers

Young Carers are classified as those aged 25 or under who care, unpaid, for a friend or family member suffering from long-term mental or physical illness, disability or drug / alcohol dependency. The upper end of the age spectrum – usually 16 to 25 – are referred to as Young Adult Carers. Much like the definition of a carer at any other age, a young carer may provide support through a combination of personal care (such as helping to dress or bathe), practical input (such as cooking, cleaning and shopping) and emotional care (such as talking through concerns). According to the last census, in Tower Hamlets there are around 3,500 young carers, with many more going unidentified. These young people potentially miss out on valuable experiences and opportunities when compared to their peers because of their caring responsibilities.

There are two lead workers for young carers in Tower Hamlets, one who works with 8- to 18-year-olds for the LA and the other with 16 to 25's for CCTH. Both key roles supporting young carers felt the support available had already been less than adequate before the pandemic, with too few formal support networks available. While very informal support networks existed, usually in the form of a family member or a professional who could be contacted in crisis situations, the lack of reliable networks that enable young carers to feel emotionally supported were concerning. The decline in support was identified as being gradual over a 12-year period, particularly in relation to services such as CAMHS and this sense of abandonment amongst young carers has led to a level of mistrust and disillusionment with professionals that is now impacting on meaningful engagement. As one of the key workers explained:

> "I remember we used to have four minibuses, so we used to ferry the kids to and from the support sessions. Now we've come back, we don't have that anymore, so how are we meant to get these kids to the session? How can I tell the parents to bring these kids to the session? The parents have got medical needs and these kids are young carers, that's the whole point … we're offering them respite, and for them to get time away. So it just seems sometimes we're offering them something that's just going to add even more pressure and anxiety to the situation that they're already in."

The experience of Young Carers

The LA run two group sessions per week supporting those aged 8- 12 and 13-18 years old who often have low awareness that they are carers, and some of the youngest of whom have their own needs, with conditions ranging from ADHD to autism, meaning that these children most likely fit the criteria for accessing support for themselves but are in the role of caring for a family member.

> “I think the sad thing is how oblivious everybody is that children actually are carers. For example, if a parent goes into hospital and comes out needing long-term looking after, and there’s only a child at home, then the child becomes the carer. I think as adults we are really bad about acknowledging that kids are carers”.

One of the issues that emerged from talking to young carers and those in health and social care organisations was the lack of awareness of young and young adult carers and several theories emerged as to why they might prove hard to reach. A chair of governors at a local secondary school shared their insights on this issue:

> ‘’There are 1,500 students in my school from 11-18 and of that number, only 4 identify themselves as carers…. when you consider that TH is one of the most disadvantaged boroughs in the country, with over 50% child poverty, and a large number of Bangladeshi students, many of whom would not see themselves as young carers because it’s part of what they do within the family situation. I think that’s rather concerning as, while of course families are very supportive of each other, it is important to recognise there are considerable stresses and strains of having caring responsibilities as a young person.’’

This was echoed by young carers across different communities who did not initially recognise themselves as carers as they felt that this role was more of a duty. There was also a view expressed around there being a degree of expectation from relatives and other members of the community that they should take on this role, which led to some young carers feeling overburdened, lacking in choice, and demotivated:

The experience of Young Carers

> ''I disconnected from the social world. I wasn't socialising with friends; I wasn't socialising with anyone because I felt like no one understood what I'm doing. In a way also, because I am so ambitious - I had such high expectations of myself. Then, becoming a carer, it felt like it took me a step down from all those ambitions and I felt like a failure, like I didn't want to achieve anything, and it was difficult to be honest.''

Young carers services in the borough were found to offer a range of support including Carers Needs Assessments, workshops, training, social activities, signposting, and referral to specialist services like CAMHS. However, young carers reported finding it hard to accept this support through their reluctance to recognise that they are an informal carer. One young carer shared that having fully embraced their caring role and duties without defining themselves as an informal carer this prevented them from seeking support for some time:

> ''For me, I was doing things that were embedded in me from my culture, from the community, so it didn't seem like I was doing anything different. It made it more difficult to ask for help because I felt like I should be able to do it - everyone else is doing it so I should be able to, that's my role. It made it more difficult to then turn around and say, 'I've had enough, I need a break, or I need help'. Now as I grow older and with the support available to me, I realise actually it's okay to ask for help, it's okay to take a break.''

Support services and provision available to young and young adult carers is perceived by some as being somewhat limited. This was identified as particularly concerning during the Covid-19 pandemic with the closure of schools and places of education, where a young carer may first be identified and start accessing support. One Social Prescriber described their experience of trying to support a young carer:

The experience of Young Carers

''I had a young person caring for their mum and they felt a bit stressed as university was only online and they struggled a bit and I couldn't provide the support needed apart from signposting to Talking Therapies... I think there was a barrier there sometimes of how best we can help these young carers when they're going through so much stress and there's no specific support service provided for them.''

Some young carers shared finding themselves in extremely complex situations where they felt overwhelmed by the challenges of juggling education, their own health and wellbeing, and supporting family members as another Social Prescriber described:

"I had a patient I was supporting, and all the children in the family have some sort of disability ... the eldest daughter has MS and still has quite a lot of caring responsibilities. She suffers as a patient herself but is also caring for her mum and her siblings and seems to always fall into this gap in terms of services. I think some work around support for specific experiences and conditions might be really helpful in this situation.''

At the LA young carers group, several carers described the impact of the pandemic on their mental and physical health and how this intensified during lockdown:

''COVID-19 has impacted us a lot. Especially when lockdown first happened back in March. My dad because he's very vulnerable, couldn't leave the house at all, not even for walks. It's lucky we have a garden to walk in, but he became very needy, wanting social interaction. I could not have 5 minutes alone without him as he would come knocking on my door 'come and talk to me, come and talk to me' or 'I'm bored'. And because he couldn't leave the house... me and my sister were his only source of social interaction, so it became a lot for us. We couldn't even have any time away from him to be on our own or to get on with our schoolwork... he was constantly there. It really did affect us, mentally as well as physically.''

The experience of Young Carers

Another young carer talked about the impact of being unable to access respite or connect with others to pursue activities in relation to their own mental health and wellbeing:

> ''It's been really hard during lockdown because although stuff is available online, it's really isolating and a bit depressing because you're still in the same environment in the same situation and you're not getting away from it all and having any 'you' time somewhere for yourself …. and actually, to get any kind of relief. A break is really missed for me, I kind of feel like I'm going mad doing the same thing over and over again in the same environment and it's just a lot to deal with.''

The experience of Young Carers

The CCTH Young Adult Carers Project was identified as a life saver for many who shared their experience. Prior to Covid-19, young adult carers were able to meet others of similar age, attend weekly respite sessions, enjoy days out together and receive 1:1 support. During lockdown, the young adult carers continued to meet weekly via Zoom, and many emphasised how important this had been:

''I found out about the group when I registered with CCTH as a carer for my dad…. when I went to this group, it felt more comfortable because people were my age…. their experiences were similar to mine, and we were all going through similar things and at the same stages of our lives. So, it felt more comfortable talking to them, sharing experiences together, and being around them. ''

This function of the group as a means of connecting with other young adult carers was regarded by many as being key to enabling them to continue in their caring role and the importance of getting mutual support was highly valued and helped them retain their ability to cope:

''When this group came about…I had thought I was always - not the only one - but amongst a small group that were doing it. I didn't realise there were so many other young carers out there.People that are younger than me as well.Then joining this group, I think it made things a lot easier. It gave me a strong support system.''

This low level of awareness can impact on a child's perception of their role as a carer and they frequently frame their situation as 'normal', as the LA Young Carers Lead explained:

"The children will say, "Oh, I can't come to the session because I need to help my mum with this," or "I need to help my mum look after my sister." And when they do come and have a little bit of enjoyment, they feel really bad as they think, 'I'm here having fun, mum or someone is at home looking after someone else, that's where I should be'."

The experience of Young Carers

Referrals for the youngest carers come mostly from schools or a self-referral from the parent. They could also be via Children's Social Care. Young adult carers primarily referred themselves or were referred by family members who came across the CCTH website. The next highest referrals were from Adult Social Care, though this number could not be described as 'high.' There was agreement among key workers that there were virtually no referrals for any age group from CAMHS (1 referral in 2.5 years), CMHT's (0 referrals), Community Nursing (0 referrals), GP's (1 referral in 2.5 years), Adult Disabilities Teams (0 referrals) and sixth form colleges (2 referrals in 2.5 years) despite significant attempts at outreach by both LA and CCTH workers, which is a cause for concern.

"I spoke to the manager of the Adult Social Care Team and explained my role and the fact that I keep coming across young people who are caring for their parents and Adult Disabilities Team know nothing about these kids, and we agreed we need to interlink a lot better, so I sent out an email recently to all the localities, so hopefully that will lead to more referrals."

Work with the 13–18-year-old age groups was described as very challenging by the LA YC Lead unless awareness raising about their caring role is undertaken when they are much Younger. Both CCTH and LA key workers agreed about the potential impact of this on long term mental health and wellbeing. There was a sense that the invisibility of these children and young people mean their contribution is overlooked until a crisis occurs, so there is a need to ensure that they are proactively identified and offered support as early as possible. The CCTH worker said:

"For example, there's a young adult carer who has long term mental health issues who is very articulate, very intelligent in a way that a lot of young people aren't about mental health as it's a very stigmatised issue, but this person feels comfortable opening up to me and so I know a lot of detail about their history and issues related to their mental health. I can be there like a cushion to deal with immediate outpourings but can't give the kind of intensive therapy that is clearly needed. They feel they can't talk about it with the family and have had poor experiences with attempts to get professional help from MH services…"

The LA key worker echoed similar concerns:

> "We need to pay attention to this … actually these kids need money pumped into supporting them as if we don't, they're going to end up in the judicial or mental health (MH)system like other kids who have been failed …"

Both key workers agreed that the support needed is simply not available and that the assumptions made about informal networks in relation to young and young adult carers are not there in reality. CCTH are responsible for undertaking Carers' Needs Assessments and are aware that assessments have been designed to rely initially on family or informal support networks, but staff know that this approach is often not viable:

> "If informal networks were able to provide support in the way it is assumed, services wouldn't be seeing so many young carers in urgent need of help. You don't need a form to say, "Have you thought about asking this friend or relative for help?" because inevitably the answer is, "Yes, of course, but they won't help!" For example, I did a Needs Assessment with someone whose family lives in the same block, not even around the corner, and they won't come and help with the caring. I regularly see young people whose families live in the same house and won't help with any of the caring responsibilities."

A vision of a community who are responsive and supportive of one another is clearly a desirable aspiration, but felt to be idealistic, and in the view of both young carers and those working with them on the front line, wholly unrealistic.

> "There has to be some building blocks of how you're going to reach a goal… you don't just assume that families are all wonderful and fully functioning, and they'd love to give a hand if they can".

One keyworker felt that without acknowledging the lack of support available, it may take a serious case review for the matter to be addressed:

The experience of Young Carers

> “Unfortunately, it can take a disaster before meaningful change occurs… the point where you’ve got young people who are absolutely at desperation point. One of the young people I work with has told me on several occasions that she wants to end her life, but I’ve got nowhere to send her except a month’s long waiting list for mental health support or to present herself at her local A&E.”

Often the young people open up to the key workers because they have lost faith in other service providers or simply feel they are the only ones who will listen. There are, however, many services who have the potential to intervene and support young carers but are over-subscribed with long waiting lists which makes the young carers keyworkers even more in demand, even if they find they are not always able to offer the kind of specialised support many young carers need.

> “Some have mental health issues that have been developing since they were young children, and they live in dysfunctional, often toxic family environments…. virtually all our young adult carers are female. It’s tempting to say that this is because of the cultural demographics of the borough, which is Bengali, and that there is an expectation around females taking on the majority of care. But in reality, there will be households where there are only male children (or older male children) who take on the burden of care and they’re not reflected in our numbers, so I strongly suspect the numbers are more equal than we think, but there’s a stigma about young men coming forward as carers”.

The groups run by CCTH and the LA offer young and young adult carers the chance to get together with others in the same or similar situations and those attending have described the sessions as a lifeline. However, while the importance of such provision should not be underestimated, it is regarded by those delivering the groups as totally inadequate in terms of meeting their physical and emotional support needs:

> “We are treated like a last-chance saloon, like a safety net. But what we should be is an ‘add-on’ to support and incentivise engagement with other services. We shouldn’t be the go-to service”.

The experience of Young Carers

There is a clear distinction between young carers and young adult carers where young carers under 18 require all information to go through the parent, which means parental consent is a prerequisite for contact. This is in some ways regarded as a positive as it means that the parent can advocate for their child and help and encourage them to access support, and this is evidenced by the fact that the engagement is marginally but noticeably better with young carers than with young adult carers.

"With young adult carers, they're autonomous beings; they don't require a parent's permission to attend but because they lack life experience, they can be suspicious of everything. They associate us with Social Services, in the broadest sense, so if they get involved with us, they have concerns about their personal data, or whether their home life could be reported to some sort of authority, or could they or somebody else get into trouble… and because it's all completely new to them, there is a really low take-up rate, so for every 100 referrals we get, only 25 will engage."

Another concern is that young people are not coming forward to state the extent to which they are struggling with being a carer, and so are not accessing professionals who might be able to pick up on the signals that an intervention is required. As such, the system is not enabling a proactive approach to ensure that crises are avoided.

"I've met with some of the most senior professionals in the borough about embedding the concept of young and young adult carers from the top-down and everyone nods their heads and says, 'what a good idea', but I never hear from them again and the referrals never increase."

This issue emerged as a concern before the pandemic, but has worsened over the last two years. Efforts to reach out through educational establishments, social services, and all institutions across the sectors who are in contact with young people have not led to a significant increase in referrals. Attempts to refine the referral process have been made but this too has resulted in no increase in referrals.

The experience of Young Carers

There is an awareness that organisations being contacted are likely to be working to capacity and may well be managing staff shortages and sickness, but there is real concern that the early identification of young and young adult carers which can lead to more timely access of support is not happening.

> “It feels like we need all agencies to sit down with their teams and say ‘Look, we’ve got a real issue with young carers in this borough, what can we do about it?’… and to start developing a system whereby if you’re working with a family, you do something really simple and keep the concept of young carers in mind. If you work with a family where there’s long-term illness or disability, then you can deduce that any young people living in that family are very likely going to be taking on some kind of caring role. It might not be nursing somebody at their bedside, but it’s going to be having some kind of impact, because a parent with long term illness may not be able to parent their child properly. On top of that, just living with someone with long term illness will inevitably impact a young carer on an emotional level and this qualifies them as a carer just as much as hands on care.”

The aims of the Carers Strategy include developing carer awareness across staff teams and identifying hidden carers, as already touched on. However, there is an evident disconnect between the stated aims and the reality, particularly in relation to young and young adult carers. The urgent need identified is to embed the concept and strategy in a more directive way:

> “Nobody seems to have any power…. who is the person at the top ensuring that these policies are put into action on the ground? No-one seems to be saying to their teams, ‘From this moment on we need you to adhere to this and start assessing need by these simple criteria … use the referral form, keep it safe on your desktop and I want to start seeing a quota of xxx referrals per month’. Nothing too strenuous, or unrealistic, we just need to start seeing referrals and investigating where referrals are not happening…”

The experience of Young Carers

Where there has been success in receiving young carer referrals it is evident that these have been self-referrals or from professionals with whom the concept of Young Carers has resonated on an individual level – rather than as a result of systemic embedding of policy. These referrals tend to be from adult social care, and it would be useful to have data from tracking the number of times a caring situation involving young or young adult carers breaks down due to lack of timely intervention or acknowledgement of the pressures experienced.

In the context of integrated care, the primary driver being the support needs of a family should in theory produce solutions around how best the system can work across mental health, primary care, the acute and voluntary sector to create a responsive and appropriate support network to sustain informal carers.

> "When I first started in social care, there was a phrase 'joined up working', and it has never really happened. Born Well Living Well and the other workstreams should be a place where young carers needs are discussed but I am not involved in that".

It feels to the young carers workers that this is another missed opportunity for people to raise concerns they are aware of. So, one recommendation would be that carers with lived experience and organisations working with carers are represented in every workstream, as their presence will help ensure that issues impacting on all carers are considered at every level.

Another concern raised is the impact of caring on young carers' education and consequent realisation of their potential. Evidence shows that in addition to underachieving academically, many drop out of education altogether. Thus, there is a correlation between lack of acknowledgement of the need for and provision of timely support for young and young adult carers which means that they are likely to be disadvantaged in terms of equality of opportunity.

The experience of Young Carers

A more general point was made about the challenge of including young and young adult carers in strategic or coproduction groups, as their ability to attend may be more difficult if they are caring full time while not engaging in education. Another factor may be the perception by many that there is a code of conduct at such meetings that assumes a level of confidence or professionalism required in order to be accepted into such a group that may feel outside their realm of experience. Meanwhile, there have been dwindling numbers of young and young adult carers who are able to access the limited forms of support on offer:

> “If there was support, I wouldn’t be having to look to see where I can get money to get a minibus for them to get to the sessions…. it’s the basic things. People don’t realise, these kids are caring so they’re going to undertake all the things that adults have to do at home, vacuuming, cleaning, washing, all of these things. Who is teaching them how to do it? Nobody… and it’s an expectation that they will do it.”

Both the LA and CCTH staff who work with young carers are solo project workers, although they aim to work closely together. In the case of the LA they have no administrative support although there are other staff that support the sessions, while the CCTH person has access to administrative support but delivers the sessions alone. Between them these keyworks have experience in the field totalling almost 30 years so their concerns merit close attention.

The experience of Young Carers

“I’ve done a check for all young carers on my books to see how many are known to Children’s Social Care (CSC), and 128 out of 130 are known to CSC, but there’s no mention of their caring role. I raised this with my manager, as if a young person is known to CSC and they’re known carers, this needs to be reflected in the assessment, but nobody is doing that… so now I have to do assessments with each of the kids that attend my sessions as I don’t understand how they’re making assessments regarding safeguarding, but being a young carer is not in itself classed as a safeguarding issue.”

Some of the stories from young carers described the pressures they face in detail, such as where a parent with mental health issues needs constant reassurance from the child who should have been studying. Renewed attempts to engage with schools are underway to highlight the need to identify and support young and young adult carers, and to be aware that certain behaviours may indicate that young carers are struggling in their role.

“I felt completely burnt out and I went through quite a transition phase…. I realised I needed help for my own wellbeing and extra support practically. But it did take me a long time because I feel like there is so much stigma attached to young caring roles. It was when I was recommended by one of our social prescribers in our GP surgery, she told me about the young adult carers centre in the borough…”

“I think now I’ve realised it’s a human side, it’s nothing to do with being weak but as humans we face strong emotions sometimes in our lives and it’s like a learning curve of trying to accept that. Personally, I’ve had quite a rough time with my mental health and wellbeing as well, so for me counselling was really a big savior and that was before lockdown, so I was able to have face-to-face sessions but after that I had counselling from my university via MS Teams. It wasn’t as interactive, but it was something to help me get through that first phase of lockdown”.

The experience of Young Carers

One of the young carer's workers described how personal contacts had been the main route to being successful in creating local awareness of the issues:

"In one school where my friend works there is a good grasp of understanding about issues impacting young carers, as she will always champion them, and if she hears that a young person is having to look after somebody, she'll quickly make the appropriate referrals. But everybody else is oblivious".

There was agreement that lack of resources was one reason for the failure to provide support to young carers, but another relates more to complex layers of inadequate understanding of their situation.

"We've gone from caring to overly focusing on ensuring that KPI's are met and targets and outcomes achieved, but there is also a need to ensure accountability for marrying up these outcomes with wellbeing".

As mentioned, the reduction in numbers of young carers able to attend the sessions provided through the LA Young Carers Lead is due to cuts to transport which was previously provided to enable travel to and from the venue. Most young carers are not able to get anyone to take them to the sessions, so the travel involved limits attendance due to a combination of time and cost factors. A relatively small investment in transport would enable young carers to continue to support the person they look after with less impact on their emotional wellbeing if they can access the sessions available to them.

"It's a drop in the ocean, but actually it would transform young carer's lives and it would contribute to prevention of long-term damage going forward. When we first ran the sessions in Mile End Park, we had four minibuses, and every session, we had about 50 kids, so it shows how much of a difference having minibuses made as now there are only a handful of children able to attend".

The experience of Young Carers

Aware of the scarcity of resources, the LA young carers worker has successfully made a link with UEL in Newham, and this has resulted in their sponsoring a series of 16+ young carers' events to compliment the twice weekly sessions plus summer programme. The LA keyworker has also applied to the NHS to secure an additional £8,000 to take young carers on a residential trip but was unsuccessful. The lack of support may act as a wake-up call, as both young carers workers agree that lack of preventative interventions are likely to lead to a collapse in the caring situation and long-term mental health issues in future.

"An example of lack of support is how Poverty Funds were distributing vouchers for Early Help, but at no point did anybody think about young carers. I went to the organisation directly as I knew them from a previous role, and they supplied Tesco vouchers, so again it relied on my contacts, knowledge and networks".

The plan is that opportunities for joint working between the two young carers workers in the LA and CCTH will be made a priority to maximise the positive outcomes for the young carers and the different age groups served will not be a barrier to pooling of energies and resources:

"We should be working together because we're both delivering the same thing … the needs are the same; it's mental health respite, it's physical respite. But we need some extra funds and investment. Social prescribing just signpost, so they identify more need, but nowhere is able to meet need in a timely way as there is such a backlog. It makes no sense."

Conclusions

While the NHS and social care face a crisis in recruitment, retention, and capacity with ever increasing demand and inadequate resources, this situation is likely to worsen with the addition of the mandatory vaccination now being in place within care homes, and the extension of this to domiciliary care and hospital staff next April. This shortage of care staff may present even more challenges when setting up packages of support for carers and cared for in their homes.

Winter pressures and anticipated rise in Covid cases and seasonal flu make an already difficult situation in acute care under increasing pressure, and hospital wards are therefore unlikely to be able to ensure that carers feel they have adequate support systems in place before considering discharging patients back home.

Day care provision having switched to more of an emphasis on individualised 1:1 solutions may enable a more tailored approach to care, and will save the LA a substantive amount of money previously spent on fully staffed expensive buildings, but the likelihood is that carers and cared for will face increased fuel bills at a time when costs are rising significantly, and will spend more time at home as fewer options for activities outside present themselves. Food and clothing costs are also rising, and carers face a high level of anxiety around how they will manage all these competing pressures while seeking support in their caring role from within their informal family and social network.

Feedback suggests that it is the voluntary sector who have provided much of the support that carers need, with opportunities to meet other carers in similar situations being highly valued, but also valuing the chance to spend time engaging in activities or interests that take them as far away as possible from their caring role. In order to enjoy the respite opportunities and renew their energy as a result of these breaks, carers tell us they need the peace of mind to know the cared for person is in safe hands, and need the breaks to be delivered by skilled and reliable people, to happen regularly and often to allow for forward planning, and do not require the carer to take on yet another responsibility in order for this to happen.

Conclusions

Investment in the voluntary sector to provide opportunities to increase support is highly likely to prevent caring situations from breaking down and an over-reliance on costly crisis intervention.

The situation of young and young adult carers is of particular concern, as this group emerged as the least recognised, the least able to make a choice about whether to take on the role of carer, and the least likely to be able to access timely support. The keyworkers involved in supporting young and young adult carers could not have been clearer about their concerns about the consequences of failing to invest in these young people, so urgent action is needed to identify, support, and nurture this group of carers who may otherwise face severely limited life choices.

It is clear that all organisations and individuals working with carers who participated in this review are aware of the pressing need to come together with those with lived experience across the system to map and plan support in a way that makes best use of resources and enables ongoing review of current support and identification of unmet need.

Appendix 1: links and further information

GHealthwatch Tower Hamlets Review looking at experiences of carers undertaken in 2019: https://cdn.whitebearplatform.com/hwtower/wp-content/uploads/2020/02/21172319/Experiences-of-carers-in-Tower-Hamlets-201819.pdf

New Statesman article on impact of cut to Rethink service
https://www.newstatesman.com/politics/crumbling-britain/2021/01/austerity-cuts-pandemic-coronavirus-covid-19-carers-clap-losing-funding-support-tower-hamlets

Healthwatch TH Carers Review:
https://cdn.whitebearplatform.com/hwtower/wp-content/uploads/2020/02/21172319/Experiences-of-carers-in-Tower-Hamlets-201819.pdf

House of Commons Briefing on impact of cuts on carers
https://researchbriefings.files.parliament.uk/documents/CBP-7756/CBP-7756.pdf

Carers UK 2019 and 2020 reports
http://www.carersuk.org/images/News__campaigns/CUK_State_of_Caring_2019_Report.pdf

https://www.carersuk.org/images/News_and_campaigns/Caring_Behind_Closed_Doors_Oct20.pdf

Unison report looking at the crisis in care staff
https://www.unison.org.uk/content/uploads/2016/11/24149_The_Damage_care_in_crisis_web.pdf

GLOSSARY of Abbreviated Terms

AUKEL: Age UK East London
CCGs:Clinical commissioning groups
CCTH: Carers Centre Tower Hamlets
CCTH YC: Carers Centre Tower Hamlets Young Carers Lead
CN’s: Care Navigators
CRS: Carers Relief Service (a decommissioned service previously delivered by AUKEL)
CSC: Children’s Social Care
CST: Children’s Safeguarding Team
CYP: Children and Young People
DI: Discovery Interviews
ED: Emergency Department (formerly known as A&E)
EIFS: ELFT Early Intervention/Family Support worker
ELFT: East London Foundation Trust
GPCG: GP Care Group
HCS: Hospital Carers Support in reach (employed by CCTH)
HWTH: Healthwatch Tower Hamlets
LA: Local Authority
LAYCL: Local Authority Young Carers Lead
LBC: London Buddhist Centre
LD: Learning Disabilities
MH: Mental Health
NIP: Neighbours in Poplar
OPRG: Older Peoples Reference Group
PET: Patient Experience Team
RLH: Royal London Hospital
TTL: Talking Therapies Lead
THT: Tower Hamlets Together
UEL: University of East London
WFH: Working from home
WTG: ELFT Working Together Group

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Groups:
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The many individual carers who shared their experience with the team

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Contact

GP Care Group Patient Experience Team	**www.gpcaregroup.org/your-health-services/patient-experience-team/** **Contact the team:** **thgpcg.patientexperience@nhs.net**