# Healthwatch Hackney and City and Hackney CCG

# Report

# Headway East London:

# August 2014

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**Specific Services Accessed by Members plus Feedback:**

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## Background

### *Acquired Brain Injury*

Acquired Brain Injury (ABI) refers to stroke, traumatic brain injury (head injury, for example through road traffic accidents), oxygen–deprivation, (for example due to carbon monoxide poisoning), brain tumour, and infections (for example, meningitis).

It is estimated that 1 million (minimum) people in the UK are living with the long-term effects of brain injury (- figure from Headway UK).

ABI typically results in:

- Physical disability (hemiplegia, mobility aids including wheelchair use)
- Cognitive disability (memory impairment; impaired executive skills – thinking; planning; impaired social judgment; and disinhibition. These difficulties can affect behaviour, including difficulty managing anger and inappropriate swearing or sexual comments / actions.
- Communication disability (aphasia; dysarthria; cognitive communication disability.)
- Sensory disability (hemianopia; difficulties with proprioception; hypersensitivity, impaired taste and smell.)
- Fatigue: physical and cognitive.
- Low mood, depression, anxiety and frustration, due to organic factors and lifestyle changes.
- Limited insight into the effects of their brain injury and the consequences for themselves and others.

ABI can be caused by, but also cause and co-exist with significant medical conditions. These include diabetes, HIV, hepatitis, TB, epilepsy, chronic headaches and migraine, pain and orthopaedic problems. Pre and post brain injury, survivors may have issues with alcohol and drug misuse. This can therefore require complex medical management and polypharmacy.

The effects of ABI are typically long-term / life-long. They are different for each individual, but often affect all aspects of the person’s life, and also affect their family. Brain injury survivors typically struggle with their sense of identity. Many are not able to work or to return to their previous job, with loss of status, skills and finances. Family members often become main carers, with consequent carer burden, financial pressures and strain on relationships. Children can also be affected, including taking on a carer’s role. Social networks: relationships with friends and colleagues shrink, leaving the brain injury survivor and their family socially isolated. Many brain injury survivors are left financially vulnerable and in debt due to the limits of benefits and difficulty managing paperwork and budgeting. They can also show reduced social judgement leaving them open to financial and other exploitation.

Physical and cognitive disability can limit participation in activities of daily living and in leisure activities, resulting in frustration, boredom, de-skilling and carer burden.

Without specialist support, brain injury survivors and their families can struggle to navigate social services assessments, benefits claims and access to medical services, resulting in further difficulties and deprivation. They also have difficulty knowing what non-statutory services are available and how to access them. Apart from distress and failure to reach their potential, this can result in deteriorating health; reduced independence and higher costs for health and social care.

There is a high level of safeguarding amongst this client group due to physical abuse, for example, domestic violence; self-neglect; violent or abuse behaviour towards others – often family, including children, and financial vulnerability.

### *Headway East London (HEL)*

HEL is a local charity affiliated to Headway UK; characterised as follows:

**Mission:** Supporting people affected by brain injury

**Vision:** A community where people with brain injury are valued, respected and able to fulfil their potential to lead full, active lives

**Values:**

- Respect the distinctive worth of every person
- Co-Production; all people have something to contribute to Headway East London and the community
- Empowerment: Support and challenge people to take personal responsibility for themselves and lead fulfilling lives within the community

**Action:**

Help people with a brain injury regain quality of life through a wide range of services:

- Headway House - a community centre for people who are living with the long-term consequences of acquired brain injury (ABI).
- Young Person’s Group – 18 – 30 year old brain injury survivors have their own group within Headway House in recognition of the needs of their age group and peer support.

- Young People's Network - a free service offering monthly social opportunities for younger brain injury survivors.
- Community Outreach: Advice and Advocacy plus Carer and Family Support
- Occupational and Volunteer Programmes
- Specialist Support Worker Services
- Specialist Therapies (Physiotherapy, Occupational Therapy, Counselling)

Respite - for family and carers and for the Members.

Activism **-** challenging preconceptions, pushing for policy change and asking difficult questions.

Headway House and the Young Persons Group are attended by residents of 14 boroughs of NE London and parts of Essex. These boroughs include City and Hackney. Placements at Headway House and the Young Person's Group are funded, typically by Social Services as part of a care package.

**Research Process**

18 Members from Hackney and 1 Member from City (the only Member from this borough) were interviewed for Healthwatch. In terms of the type of brain injury sustained, the City Member had a stroke, as did 5 Hackney Members; with 3 other injuries caused by brain haemorrhage.  TB Meningitis caused a brain injury for 2 Hackney Members; brain tumour for 1 Member, with the remaining 7 Members sustaining a traumatic brain injury.

Due to the high level of cognitive and communication disability of Members, interviews were typically carried out on a one to one basis, with a small number of paired interviews. Adapted materials to support communication, for example pictures and rating tools were used where necessary. Members were assured that their contributions were anonymous, and all were willing to contribute to the project aim of improving services and access.

Consequences of some Members' cognitive disability, for example their memory problems and lack of insight included difficulty recalling services they accessed and problems that they or their carers had previously reported. Members were therefore prompted in interview to support specific recall. In addition, staff members who act as their Key Workers have offered supplementary feedback. In one case, a Member's wife (main carer) was interviewed in place of the Member due to the extent of his cognitive disability.

## Summary of Feedback

### Question 1): How well do residents from your client group know what health and social care services are available?

### + Question 3): Do your client group get timely and good information once they are using a part of the health or care system?

Question 1 and 3 can be answered together.

The key NHS relationship reported by many Members was with their GP. This was typically reported as positive in terms of responding to health issues within the surgery but limited regarding referral / sign –posting and support to access other services including health related services. This pattern matched that of some Members' relationship with another key health professional: their Neurologist. Specialist Nurses (Epilepsy; Diabetes) were described positively, including for more general support / advocacy regarding care needs, but few Members reported accessing these services.

The key Social Services relationship for Members was with their Social Worker. However, only one could name their Social Worker and typical feedback was of negative experiences of negotiating a care package. Exceptions were where Members specifically recognised themselves / their family as articulate and 'able to fight' for what they needed. Headway East London staff were also identified as helping to negotiate with social Services.

Even when Members were signposted or offered options, they typically found it difficult to access these. This is in part due to the high level of significant cognitive and communication disability amongst Members. This affects information processing, understanding, reading, memory, planning and problem solving, speech, writing, initiation, and insight. Consequently, most Members have a limited idea of what health and social care services are available for them.

This is the case, even where information has been 'timely' as most will need active support to access services. They also sometimes require support to recognise their need or benefit, due to poor insight into their disability and its consequences. This kind of support often requires trust; built up through a long term relationship.

There are a few Members who are participating in many community activities and feel confident to access the health services they need. However, these Members typically have one or more of the following factors in their favour:

- insightful;
- affected more by mild – moderate physical disability rather than cognitive or communication disability;
- a pre-morbid history of accessing (and even setting up) services;

- a supportive family.

In the experience of HEL, family and carers vary significantly in their ability to find out about resources and services and recall them at times when these are relevant. Brain injury has a significant impact on family members; often resulting in a much larger caring role, with effects on work and other roles, financial worries, fatigue and carer burden. Carers themselves can lack insight into needs and difficulties and it can take a long time for their awareness to grow and for them to accept help.

When faced with health and social services assessments both Members and family report conflicting drives: highlighting difficulties versus 'focusing on the positives and the things achieved'. Another strong factor can be shame at revealing difficulties and asking for help. Many have limited faith in statutory services: either historically or because of a bad experience post brain injury. Building up a trusting relationship and exploring options can take a long time. Acquired Brain Injury is a long term (life-long) condition, but relationships with health professionals or social services are typically short term. Exceptions to this are GPs and Neurologists.

**Question 2): What are the barriers to accessing health and social care services for your client group?**

In addition to the barriers caused by the nature of disabilities post ABI mentioned above, the following are key barriers:

- Inadequate care packages (funding and provision):
  - lack of provision of support for community health access; advocacy with formal appointments, help with paperwork and finances; resulting in poor access to and use of available services.
  - lack of provision of paid carers / support workers who are trained in ABI. This results in activities being done for Members by generalist carers with short time slots, rather than Members being facilitated to participate as much as possible using strategies. Consequences include de-skilling and reduced confidence and motivation. This can undo achievements in rehabilitation under the NHS.
  - lack of provision of appropriate support for regular /daily exercise programmes e.g. physical, gym, swimming, communication; mood management etc. This typically limits progress and carry-over, and again, can undo achievements under rehabilitation.
  - lack of provision of appropriate specialist support workers and lack of funding for placement in specialist centres such as Headway House where peer support, social opportunities and engagement in meaningful activity are facilitated, and cognitive and behavioural issues are positively managed.

- Inadequate transport options, including costs for carers (no Freedom Pass); and difficulty with bookings and delays with Dial-a-Ride. This results in reduced access to the community services available; particularly leisure and social activities.

- Poor communication between health and social services. HEL staff have experienced Social Workers declining to engage with health professionals such as therapists as well as with themselves in order to complete an adequate care needs assessment and establish an appropriate care plan. This appears to reflect a failure to properly acknowledge the integrated nature of health and well-being.

- Limited availability of Advocacy services with specialist ABI knowledge and experience.

Family and Carers often end up compensating for these inadequacies, resulting in carer burden and impacting on their own health and well-being and well as on finances and other family relationships. Family members often describe social isolation and a negative impact on their identity as much as Members**.**

**Suggestions to Help**

- ***Improved communication and coordination between health and social services is essential.*** The Headway East London Community believe that it is not possible to offer effective support for brain injury survivors and their families where Health and Social Services are separated. Members are supposed to have a care package review by Social Services on an annual basis and many have an annual (six-monthly) Neurology review. Ideally, this would be integrated, as it is in many in-patient rehabilitation facilities, and would include access to community therapists and relevant specialist nurses, to support a review of needs and options to address these. This could also help address issue of polypharmacy and support information on health conditions and medication being provided in accessible ways (simple wording; pictures etc.) Members and family should be actively involved. The views of other significant people involved in their care, such as HEL key workers, should be actively sought as part of the assessment process, and to explore solutions. Care therefore becomes ‘person-centred’.

- ***Acquired Brain Injury Specialist Social Workers.*** As noted in this report, acquired brain injury is a complex condition, in terms of recognising needs, communicating appropriately with brain injury survivors and working as part of an multi-disciplinary team (including health professionals) to form and sustain an adequate care plan. Such social workers are often part of specialist in-patient rehabilitation. Due to this complexity, other boroughs have elected to have specialist social workers for service users in the community also.

- ***Statutory Case Managers*** (via Health and / or Social Services) to coordinate care for brain injury survivors with complex needs, on a long-term basis; across Health, Social Services and Third Sector services. This would support families with high carer burden and help brain injury survivors with a limited support network.

- ***The impact of acquired brain injury on identity, and the effects of cognitive and communication ("hidden") disabilities, should be better recognised by Social Services, including the need for carer respite.*** This would be reflected in their classification of care need levels. In consequence there should be adequate funding for specialist ABI support workers and placement at specialist centres such as Headway House. This in turn could improve use of health services and use of opportunities to build skills, confidence and social networks. This could reduce longer term costs to both Health and Social Services associated with de-skilling; carer burden and breakdown in family relationships and deterioration of physical and mental health.

- ***Improved provision of transport options*** to access community services, including social groups, for example dedicated transport such as is used by some Day Centres. This should include support to book journeys and ensure paid carers time washing and dressing plus meal provision appropriately.

- ***Improved access to specialist acquired brain injury advocacy*** rather than 'generalist' disability advocacy, to ensure needs are adequately recognised and supported.

### *Headway East London*

Headway East London offers long-term, holistic and integrated support for Members and families – through peer support, staff support, key working, advice and advocacy; allowing needs to be recognised and solutions explored. Headway House, the Young Person's Group, and the support groups offer a positive social and support network to compensate for what has been lost post brain injury.

The emphasis on co-production encourages Members to contribute to the Headway community; sharing and developing skills; gaining confidence and building a new sense of identity. The specialist support worker service facilitates maintaining health and well-being, for example through helping with paperwork, formal phone calls and appointments, as well as practical skill building (shopping, cooking). These services encourage community participation: through projects such as pop-up restaurants and art exhibitions, and one to one vocational activity such as college attendance and voluntary work.

Headway Therapists work with Members one to one and in groups to further specific practical skills and mobility, support management of mood, and provide strategies for Members, family, support workers and other staff to help with carry over into everyday tasks. Support workers help with regular exercise, gym and swimming, to maintain and improve health.

Key workers, the Advice and Advocacy Worker and the Family Support workers advocate for Members and families with statutory services, and support awareness of and access to a range of community services including other third sector options. The long-term nature of this support helps to develop trust with Members and families and supports negotiation and acceptance of help.

***Although one can identify and discuss abstract ideas, these can be best illustrated through individual experiences. These combine the person's own comments with comments from their key worker, and have been anonymised:***

## Case Vignettes

1) Mr. Q is in his fifties. His traumatic brain injury was over ten years ago. He has severe aphasia – he is only able to say a few words, including swearing; has a lot of difficulty understanding what is said to him and reading words, and cannot write. He cannot walk and uses an attendant-propelled wheelchair. He has always had a strong personality. He lives alone.

Mr. Q now has another severe medical condition, which requires a lot of hospital appointments. Approximately seven years ago his case was recognised as complex and his needs were addressed through a joint health and social services initiative. This meant that specialist acquired brain injury support workers were funded. They support Mr Q with personal care, meal preparation, shopping, managing paperwork and finances. They also support him to manage medication and attend hospital appointments. He can be reluctant to do this, but they have known him a long time; are skilled in communicating with him and have established a good relationship with him so his attendance is good.

Mr. Q was recently reviewed by Social Services who are cutting his care funding. The suggestion is to substitute non-specialist carers. However, when he had these previously, they struggled to understand him; resulting in relationship breakdown and him declining to let them in.

He has some limited family support but they have other difficult issues to deal with. He uses non-prescribed drugs and drinks alcohol, particularly when he is 'bored' ('not at Headway'), and is visited by friends who do the same. He is highly vulnerable.

Mr. Q attends Headway House twice a week and has done so for many years. He enjoys attending Communication Group and playing games, and has engaged in art and music projects. These activities support the maintenance and development of cognitive skills and use of strategies to help his aphasia. He has a strong network of friends at Headway but is otherwise very socially isolated and exploited by ‘friends’.

His key worker has advocated for him on many occasions with health and social services and supported his family.

Specific examples of HEL support include:

- Made a Safeguarding alert due to financial abuse, and has supported other safeguarding alerts.
- Made a third party report to the police regarding exploitation over the purchase of illegal drugs.
- Periodic home visits to check on welfare.
- Key role in negotiating with Member and family regarding support planning, then participating in support planning meetings with Sweettree specialist brain injury support work service, health case manager and social services.
- Advocacy to gain a discretionary housing payment.
- Periodic visits of family members to Headway House, for Family Support events and for 1:1 support around specific issues such as understanding and managing the Member’s diagnosis with cancer; social services reviews.
- Supporting member to understand his health diagnosis and the options and negotiating with him regarding hospital attendance. Accompanying him on some hospital appointments.

2) Mr. L is in his fifties. He had a brain injury approximately ten years ago. He lives alone. He has multiple health conditions, including diabetes and epilepsy, and has a shuffling gait, with risk of falls. He has a significant cognitive disability including impaired memory and thinking skills. He cannot plan and organise things and has limited insight into his difficulties. His disability is ‘hidden’ to some extent. He uses non-prescribed drugs and has also been under safeguarding several times due to self-neglect, debt and vulnerability due to exploitation by drug-taking friends. He had been going to the pub regularly but has now been banned; probably for issues of debt. His family offer limited support.

Mr. L needs support to manage his health and self –care. He shows self-neglect; has poor personal hygiene and has had more recent issues with incontinence. He is highly vulnerable. He has some support from specialist acquired brain injury support workers but this is limited.

Mr. L attends Headway House twice a week, and actively engages in cooking. He has a positive ‘role’ in the Headway Community due to his superior cooking skills; particularly for African –Caribbean dishes made for Lunch Club. He requires support from staff and volunteers with some physical aspects of cooking; with planning, sequencing and initiation, and with hygiene. He is also well-known in the Headway Community for his skill at dominoes, and welcomes and encourages new Members through helping them with dominoes, with prompting. He also loves music and had been a DJ prior to his injury. He has been supported to bring in his music to play at Headway and act as a DJ with support at some Headway events. Mr. L has limited spontaneous conversation and reduced attention and concentration, but has participated appropriately in Discussion Groups with support. He uses the gym to exercise, with support, and has started to initiate attending. He has attended Relaxation Groups. He has developed a long-standing network of friends at Headway and phones each day he attends to confirm that he is coming and alert staff that he will be late.

Although he typically shows poor engagement with external services, for example disengagement with a drug counselling service, Mr. L now accepts and sometimes seeks help from some members of Headway staff. His key worker and the Advice and Advocacy Worker have supported him many times with health and care issues and with debt. He has often attended Headway with no money and having had nothing to eat.

Specific examples of support include:

- Ensuring he has food (diabetic diet) and other necessities in the short term.
- Liaising with social services around serious debt and financial management.
- Providing him with specific amounts of money via the Samaritan Grant, for example to take a taxi to his GP.
- Instigating multiple Safeguarding alerts.
- Seeking legal advice regarding care services on his behalf, including proposal to reduce Headway House attendance to one day / week.
- Prompting him to go to GP when unwell.
- Investigating severe difficulty walking and in consequence liaising directly with GP regarding poor foot health.
- Alerting GP to the need for a dossette box when Mr. L was prescribed new medication which he failed to take.
- Liaising with his Support Workers to prompt follow-up of medical reviews of his shunt and his chiropody appointments. Mr. L’s shunt has blocked in the past, resulting in serious deterioration of health.
- Attending social services reviews and following up regarding need for support with appointments and deteriorating health. This included writing a letter of concern about lack of support from the family member acting as carer.
- Referral to Outward Targeted Preventative Service for further advocacy / floating support.

3) Ms. T is in her fifties. Her brain injury was approximately seven years ago. She lives with her mother who is her main carer. She has some mild - moderate physical difficulties, has dyspraxia and has a cognitive disability; needing help to process information and organise things. She also has some difficulties with anger management, for example recently shouting repeatedly at a woman who failed to give up her seat for her on the bus. This happened on a Headway Outing and staff were able to help at the time and to encourage reflection afterwards. However, Ms T had difficulty acknowledging that her behaviour was unacceptable.

Ms T enjoys attending a local Stroke Group and uses her Freedom Pass to go there on the bus, with her mother. Her mother also accompanies her to appointments and to the gym. She enjoyed attending the gym through her GP: ‘gym on prescription’ scheme but this was only short term and she wants to go long-term to help with her weight. She did not find referral to a Dietician helpful: “disillusioned”.

She enjoyed attending a disabled swimming session but has had to give this up as she needed assistance and her mother has declined to go. Also, the time was late in the evening and restricted. She does not have a support worker.

Ms T enjoys attending Headway House, as she feels “comfortable” there; finds art “calming”, and finds people “understanding” – “If I get stuck it’s not such a problem.” She attends the Women’s Group and enjoyed a recent outing; agreeing to trial new food types. She also benefits from supported exercise through attending the gym and chair-based exercise group.

She has been supported by the Advice and Advocacy Worker to request and follow up on shower repairs with her housing association. Her key worker recently supported her and her mother with her Social Services care needs review, including preparing what to say through reflecting on difficulties; giving feedback from her participation at Headway; and passing on information from her Assistant Psychologist based at St Leonards Hospital about her mood and behaviour.

Ms T has developed a trusting relationship with some staff at Headway; spontaneously approaching them for help with paperwork.

Her key worker also recently supported Ms T to cope with her distress at finding out she had been prescribed an anti-depressant by her GP, without realising this. The key worker has offered to accompany her to her next appointment with her GP, if she would like this. She has also been referred to HEL Physiotherapist for acupuncture for hot flashes.

Ms T was also anxious about being discharged from the psychology service at St Leonards after two years. Her key worker has been supporting her to manage this anxiety and has liaised with the psychologist. The psychologist requested that Headway staff use specific techniques to check in with Ms T to monitor her mood on a regular basis. Ms T has declined referral for counselling at HEL.

4) Mr. E is in his twenties. He had a severe brain injury two years ago and has epilepsy and asthma. He is also awaiting a further cranioplasty. He has physical weakness on one side of his body plus visual difficulties (hemianopia). He has cognitive difficulties including difficulties initiating actions and some impulsivity, as well as problems with memory and problem-solving. He is at risk of falls, and uses an attendant-propelled wheelchair outside.

His main carers are his parents and they support him with most activities at home and also accompany him to appointments and community activities. They speak limited English. He has no support worker but would like one. There is not currently funding available for this.

Mr. E goes to Ability Bow once a week and to the Stroke Project once a week. He was initially supported to attend these activities and also the HEL Young Persons' group through the Homerton Transitional Rehabilitation Unit (NHS). HEL supported this NHS project by prioritising HTRU service-users on the waiting list for HEL placement. The aim of the project was to offer a seamless transition between in-patient rehabilitation and access of community services on return home. Funding would then move from NHS to Social Services.

He attends the HEL Young Persons' Group (YPG) once a week and enjoys the people, outings and games. The YPG offers vital peer support from brain injury survivors of his own age group. It provides an opportunity to socialise and get involved in a range of art, music and cooking projects and activities, which build practical and cognitive skills. Crucially, his time at the YPG affords respite for his parents and an opportunity for him to be independent from them. Mr. E has requested to engage in physiotherapy at HEL, and has been referred to HEL Occupational Therapy for support with his weekly routine and poor sleep routine.

His key worker has supported him and his family through, for example, liaising with GP regarding Botox; liaising with family regarding his cranioplasty and need to wear a safety helmet; and negotiating with Mr. E and his family due to inappropriate behaviour, impulsivity and rudeness (sending offensive texts).

His key worker is also helping him and his family with an application for a Blue Badge (disabled parking badge), at their request. Mr. E currently uses Dial-a-Ride but this is unreliable, for example often delayed by over an hour with journeys to and from Headway.

5) Ms. O is in her forties and lives with her partner and two young children. She had her brain injury approximately ten years ago. She has epilepsy and valued the support of an Epilepsy Specialist Nurse who used to visit her at home, but she has now been discharged. There have been safeguarding concerns due to her partner's behaviour and Social Services have declined to visit her at home. She uses a wheelchair which she can self-propel for short distances. She has a paid carer for

personal care and is otherwise reliant on family support at home and to access the community.

Ms. O has short and long-term memory impairment; low mood and some inappropriate social behaviour including irritability. She has some absence-type seizures and staff support her with these. She identified attending Headway House as the only thing she does in her week, and likes physiotherapy and exercise therapy and meeting people: “not lonely”. Otherwise she would be “low” and “bored.” She also enjoys outings and the Women’s Group. Her behaviour can often be negative and she benefits from staff and peer support with this, to encourage more positive participation. She produced some artwork for the recent Art Exhibition at Canary Wharf and enjoys art. She reported that she used to go for physiotherapy somewhere else but “had to pay for the lesson and the transport”, and ‘couldn’t afford it’.

She has received advocacy from her key worker and other HEL staff on several occasions, including around care needs and services. HEL staff have been involved in investigating safeguarding-type concerns due to Ms. O possibly being subjected to domestic violence by her partner. This has involved liaising with other professionals involved, including her Epilepsy Specialist Nurse who was visiting her at home. However, she has now been discharged from this service. Social Services have declined to visit her at home due to the behaviour of her partner. HEL offers vital respite for both Ms. O and her partner, and provides an on-going opportunity to monitor her well-being. Her key worker is also talking to her about difficulties with one of her daughters at school. This has prompted the school to request observation of the family at home, but her partner has declined to engage.

Her partner and children have engaged in some Family Support activities at Headway House, including Family Day, where carers offer each other peer support. Through a specific HEL initiative, her children took part in activities aimed at supporting children whose relatives have a brain injury and understanding more about brain injury. They were also provided with age-appropriate booklets to help their understanding.

Ms. O has received practical help from the Advice and Advocacy Worker, for example regarding requesting and following up on a door repair. HEL provides supporting information for social services assessments.

**Further Recommendations:**

The key role of families in supporting brain injury survivors has been emphasised in this report. However, due to the focus of this research project, only one carer has been interviewed, in order to represent her husband. It is therefore recommended that further research be undertaken specifically into the needs and experiences of families of brain injury survivors.

## Specific Services Accessed by Members plus Feedback

### 1) GP

Members rated their GPs as follows- Very Good: 5   Good; 4   OK:  7    Poor: 1

Other: 2 - “sometimes good”; “have to visit repeatedly and be quite insistent.”

7 Members reported support to set up the appointment and reported being accompanied to the GP to act as advocate; most by a family member and others by paid carers. Others reported attending appointments alone. The carer reported taking responsibility for setting up, taking her husband to and advocating at appointments.

### *Barriers and Information – Giving*

HEL staff who act as key workers or advocates for Members reported a higher level of difficulties with GPs; particularly getting appointments and failure of GPs to communicate effectively, for example, giving Members information which they were unable to fully understand and recall. Staff have also needed to inform GPs of medical difficulties for some Members, for example difficulties with foot health, where Members do not recognise the nature and consequences of their condition and do not initiate requesting help themselves.

Cognitive disability (memory impairment, executive difficulties and reduced initiation) as well as communication disability particularly affects Members’ ability to make effective use of their GP, as well as accessing the surgery.

One Member reported selecting her GP due to the fact that they were near to her home but said that is she had better transport options she would change GP.

### *Helpful factors described about their GPs:*

- the GP texting appointment reminders and communicating with carers about appointments where necessary. (The need for this is sometimes flagged on notes which is useful.)
- the GP offering home visits when necessary (1 Member);
- the GP knowing them and their health conditions well, so there was no need to explain background information;
- the GP providing double appointments to offer the necessary extra time,
- the GP phoning Members back quickly, even if appointment slots are delayed; offering quick appointments where the issue was judged urgent.
- the GP ensuring Members had copies of correspondence so that referrals could be tracked and to help with memory problems.
- the GP referring them for further specialist medical services and therapies – particularly gym on prescription, *please see below*.

- some Members have expressed interest in the idea of GP surgeries taking a role in sign-posting them to services, for example through ‘social prescribing’.
- Many Members need support and advocacy to identify when they need medical help; support to make the appointment and to travel there; to advocate for them in appointments and to support recall, understanding and implementation of treatment. This need should be recognised as vital in Social Services Care Needs Assessments, and carers /support workers funded.

## 2) Medication

### *Barriers and Information-Giving*

Members reported more concerns in this area.

11 reported struggling to understand what their medication was for, and reported needing help to renew prescriptions and ensure they were taking it correctly. Quite a few Members take a few different medications. One commented that his medication is often reviewed at the hospital and frequently changes, which he finds confusing.

Additionally, 4 Members who reported having no problem coping with their medication independently have been supported by HEL staff, for example, to understand the condition their medication has been prescribed for and / or support them with strategies to ensure they are taking their medication appropriately, for example, setting reminders; requesting a dossette box.

Some Members had a basic idea about which condition their medication was for, for example, “It’s for my epilepsy”; “it’s so my TB doesn’t come back”. However, they showed a reduced grasp of how the medication worked, for example feeling able to adjust their own dosage / timing without consultation.

A couple of Members reported relying on discussion with informed relatives to support recall and decision-making about medication. The carer reported good awareness of her husband’s medication whilst he had poor awareness.

Cognitive disability (memory impairment, executive difficulties and reduced initiation) as well as communication disability particularly affects Members’ ability to manage medication effectively. Many members have multiple health conditions resulting in complex medication regimes.

### *Helpful strategies for managing medication:*

- Extra time with GPs to discuss medication plus automatic reviews.
- Appropriate simplified written and pictorial information about the nature and purpose of medication. This has sometimes been provided by GPs,

but has also been provided by HEL staff and community therapists. A difficulty is keeping this up to date, however. Specialist ABI Support Workers (SweetTree / Headway East London) are experienced with this and support some Members effectively.

- Dossette boxes.
- Automatically repeated prescriptions. One Member reported that Boots used to contact him every 2 months to inform him it was ready for collection but that his local Pharmacy requires him to go in and order it. Another reported monthly home deliveries.
- Access to specialist nurses, for example Epilepsy Nurses. Some Members reported that it was easier to discuss their medication and other related health issues with such professionals as they were approachable; met them more frequently; could be accessed by phone to discuss issues; provided better information and they liaised on their behalf with GPs and Consultants.
- Polypharmacy has been identified by staff as common with Members, due to co-occurring and complex health conditions. This requires careful monitoring and has required advocacy from keyworkers and other staff to ensure the best regime with minimal side-effects.

**3) Hospitals and Clinics**

Members showed significantly more difficulty recalling their hospital and clinic attendance and reported a higher level of support attending these appointments. Neurology was the best recalled: via the Homerton Hospital and via the National Hospital and positive comments were made by Members regarding their relationship with the Neurologists.

The range of medical follow-up for Members is indicated below; highlighting the complexity and co-occurrence of significant medical conditions in this client group.

Neurology Follow-up: Homerton Hospital: 8

National Hospital for Neurology and Neurosurgery: 2

Neurosurgeon re shunt review:1

Blood Tests:2

Diabetes Clinic:1

Epilepsy Nurse Specialist:2

Eye clinic at Homerton Hospital:1

Moorfields Eye Hospital: 1 - ok but doctors always changing

Sensory Team: 1

Community Nursing: 2 (poor service re home visits reported by 1 Member.)

Wheelchair clinic: 2

Hearing: 1 due to HEL referral.

A and E: 1 due to poor self-management of alcohol misuse

Cancer follow-up: 1

Liver Specialist: 1

Kidney Specialist: 1 “fantastic” – Royal London Hospital Consultant keeps well-informed + phone calls to remind re appointments

Drug and Alcohol Service: none reported at this time, despite staff identifying at least 3 Members with these issues.

More Members reported being accompanied to hospital appointments than GP appointments; typically by family members, and said this was important for advocacy; to “make sure I tell them what I need to.”

Family / friends accompany: 10

Support Workers accompany: 2

3 Members reported good experiences with their appointments but delay or difficulties with promised referrals to other services.

Hospital transport was also commented upon: positively by one Member but negatively by another who commented that it was frequently delayed: ”late”.

**Barriers and Helpful Strategies were largely similar to those identified for GPs and Medication. However, advocacy was identified as very important by the majority of Members, due to the predominance of cognitive and communication disability.** This included monitoring the person’s health; setting up appointments; chasing up services; reporting on symptoms and supporting suggested intervention. Many family members had taken on this role. This was hard to fit in where the family member was working, and for the carer interviewed, she found caring for her husband a full time job with little respite.

Support Workers / paid Carers are allocated the role of supporting hospital and clinic attendance for some Members. One key worker identified inconsistency in hospital attendance for one Member and reported that a reduction in Support Work had contributed to this. Other barriers to success in this role can be lack of knowledge and experience of brain injury and inadequate use of strategies to support the Member effectively. Additionally, breakdown can occur due to lack of trust / poorly established relationship with the Member. HEL recommends Support Worker Services such as those provided by Sweettree or HEL themselves.

Where family were not acting as advocates to support medical treatment, key workers and other staff at HEL typically took an active role in identifying health concerns and liaising with GPs and other medical professionals to ensure intervention.

HEL Staff often take a role in:

- identifying the need for health intervention for Members
- discussing this with Members and significant others
- explaining risks and options with Members and negotiating with them
- making and / or following up referrals

Staff, typically key workers, have accompanied Members to hospital and clinic appointments where necessary. In addition to requiring advocacy due to cognitive and communication disability, several Members feel very anxious about health appointments and / or struggle to keep their temper, for example if they are kept waiting or there are administrative tasks, due to disinhibition.

HEL staff have usually built up strong, supportive relationships with Members over a long time, resulting in Members trusting their views more. The health issues staff have identified and acted upon range from more serious gastric / liver / neurological (TIA; blocked shunt) concerns to more standard concerns. These include issues associated with ageing: Dental and Opticians (where GPs would not typically organise referrals); Hearing and Podiatry. In one case a Member had such bad foot health it was seriously impeding his walking. Another Member reported disliking attending hospital and often initially refuses to attend. His key worker negotiates with him using communication strategies to manage his aphasia; usually persuading him and then liaises with his Support Worker.

### 4) Social Care

2 Members reported a named Social Worker and reported a positive experience of their recent Care Needs Assessment. Both regarded their success as due to being articulate about their own needs and being well-supported by family in the assessment.

9 Members made negative comments about their experiences of Social Services including their Care Needs Assessment. These included:

- “not feeling listened to”;
- “not understanding about brain injury – they think I’m all right because I’m walking about but I’m not sleeping, I get angry quickly, ….I have fits…. I can’t understand what they’re saying.”
- “they put you in one box. I look agile but… I am overwhelmed with paperwork and trying to sort everything out…I’m intelligent but I have a learning disability.. I’m not getting any support.”

Other Members were unable to recall Social Services involvement or commented generally that their family and / or HEL helped with this.

The range of care offered included:

SweetTree Specialist Acquired Brain Injury Support Work Services: 2.

One Member is at risk of having this service cut; which his key worker reported will place management of his health at significant risk.

Supported living: 1

Family Member as main carer: paid: 1

unpaid: 8 (practical support and / or advocacy)

Non-specialist paid carers: 4

One Member reported dissatisfaction with paid carers “not turning up”, and was unclear regarding their exact duties. The Carer reported that following a Carers’ Assessment, her husband was provided with paid carers am and at night to help with personal care. However, she said that she cancelled the carers and took on full responsibility herself in an unpaid capacity. She said that this was because the carers were unskilled in helping her husband and was allocated only a short time per day with him. This resulted in them doing things for him so that he lost skills that he had gained through in-patient rehabilitation e.g. shaving himself.

In each case, Members are funded by Social Services to attend Headway House / Young Person’s Group. However, the Carer and 2 Members reported concern that Hackney Social Services had increased their financial contribution level, forcing them to consider cutting down their attendance or precluding attendance all together.

Headway staff have commented that this related to the Community Care Charge, whereby people receiving the higher rate for the care component of DLA have been required to contribute more to their care costs. Disability-related expenditure is taken into account but typically relates more to practical factors such as additional laundry costs.

Headway East London have actively supported Hackney Members with Care Needs Assessments and family members with Carers’ Assessments. This has included providing reports; often attending assessments; liaising with Social Services and challenging assessments, including through legal means.

In addition to the Members above, HEL staff have reported that 7 other Members have faced personal budget cuts by Hackney Social Services in the last 1-2 years. Due to cognitive disability, including memory impairment these Members have limited understanding and recall of this. Social Services have been challenging

Members' wishes to remain with services such as Headway House and SweetTree Acquired Brain Injury Support Work services.

### 5) Therapies and Counselling

Fewer Members than expected by the interviewers were accessing therapies in the community. This included opportunities to exercise, which is identified as essential to maintain and improve physical abilities and to support general health.

The range which Members reported using were:

Adult Community Rehabilitation Team: (SLT, Psychology, OT, Physio) 3

Out-Patient Physio: 2

1 Member was referred when an In-patient for community follow-up.

Gym on prescription: 1

Another Member reported that she had been given access to gym on prescription for 3 months by her GP, which she found very successful. However, this stopped and she described gym as a "long term need." She is not accessing the gym at present. She needs support from her mother to help her attend.

Ability Bow: 1

Another Member reported being assessed there but is not currently able to access it as needs someone such as a Support Worker to accompany him as does not have this.

Home exercises: 1 + family

Accessible Swimming: this was accessed by 1 Member who had to give up as she reported that the hours were too late in the evening and limited and the attendant declined to help her. She does not have a family member who can help and has no support worker.

MIND Counselling:1 but "short term and long waiting list"

Centre for Better Health Counselling: 1

HEL: Physio - 2

    Counselling - 1

    OT - 1

***Barriers:***

- Few Members were able to identify what was meant by therapies, except for physiotherapy, and therefore what might be available.
- Few Members were aware of how to access therapies.
- Long waiting lists and difficulties with the referral process were also identified.
- Difficulty accessing appointments / activities due to lack of available family / formal support were identified.
- Costs were identified as a barrier.
- Difficulty with transportation was also identified; particularly with Dial a Ride and also with the cost and necessity of being accompanied on public transport – see below. The Carer reported needing to take her husband on 2 buses to attend Ability Bow after which he was too fatigued to exercise. She reported that Dial-a Ride was too unreliable and frustrating.
- Difficulty with carrying out home exercises and tasks to promote carry-over was also identified. Physical and cognitive difficulties often meant that Members needed specific regular / daily support. Family members were then relied upon to help, with variable ability to do so, and other Members reported difficulty accessing Support Work to help with this. Without this support, participation in rehabilitation can be poor and skills poorly sustained; placing the cost-effectiveness of such intervention in question.

***Helpful Strategies:***

- Free or low cost access to services: via NHS / exercise on prescription – long term where necessary.
- Sign-posting and referral to services made by medical professionals, e.g. post Neurological review; referral on for community follow-up by in-patient therapists on hospital discharge.
- Sign-posting and provision of services via third sector organisations such as HEL, The Stroke Association and MIND.
- Provision of therapy services specialising in acquired brain injury, in order to manage impact of cognitive and communication disability on participation in treatment more effectively.
- Low cost and reliable transport options – this has not been solved.
- Adequate support to liaise with and attend services and implement recommendations, including Support Work.
- Ideally services would be linked to other activities, as in Headway House or with community therapy provision, where staff / rehabilitation assistants are trained to facilitate the carry-over of skills into activities at the Centre and / or in the community. This includes practising indoor walking; using anger management or memory strategies in a Discussion Group or whilst shopping etc.

## 6) Weight and Diet

Some Members reported needing to modify their diet, for example due to diabetes. One reported coping with their diet as a relative was a nutritionist. However, another reported no issues, although staff at HEL regularly need to support him to manage his diabetic diet due to his cognitive disability.

One Member reported being reviewed by a local Speech and Language Therapist to ensure safe eating through a modified diet. However, the need for this and the referral was made by HEL staff, as he was choking on his food at lunchtime in the centre. Another Member identified complex difficulties around eating and said he asks his HEL Key worker to help him access medical help.

*Managing Meals*

Few Members spontaneously referred to management of meals at home, including shopping and cooking. Many find it difficult to shop and cook independently. Some have specific help from carers / support workers but rely primarily on microwave meals. Others tend to rely on family to cook for them. One Member reported cooking herself. However, she needs support with shopping and some elements of cooking from her family.

One Member reported no problems but his key worker reported that due to alcohol misuse he frequently misses meals and his mother cooks for him to try and support his nutrition.

A HEL key worker and Advocacy Worker have had to liaise with Social Services regarding support for one Member to manage his finances due to his cognitive disability and social vulnerability. He has in the past been without any money to purchase food and has required an emergency grant. In general, many Members report restrictions on their diet due to limited money.

HEL Key workers often liaise with Social Services to identify Members' needs around shopping, cooking and nutrition, including budgeting.

*Dieticians*

One Member reported on-going difficulties managing weight but was dissatisfied with the support she received from a dietician," I did what they said but it didn't work. I feel disillusioned." Another reported preferring a holistic approach to her diet over the dietician's intervention.

*Healthy Living / Cooking Schemes*

1 Member reported eating more healthily due to gardening and growing food. He volunteers with a gardening charity at the Homerton Hospital but lost funding for St Mary's Gardening Project.

4 Members named local Community Centres: St Luke’s, in South Islington, MIND and the Healthy Living Centre, Hackney as offering Cookery Classes and /or Gardening, plus St Mary’s Gardening Project, which they have used or intend to use.

*Exercise – please see Therapies above*

*Headway East London*

*HEL supports Members to manage the centre’s garden; including growing fruit and vegetables, and has also supported Members to participate in community gardening projects such as planting along the Regents Canal.*

*Produce from the Headway garden and also from local food schemes is used in the Headway Kitchen. One of the Coordinators is a trained chef, and Members with an interest in cooking are encouraged to cook lunch each day in Lunch Club for all at Headway House, and for some members of the local community. The emphasis is always on healthy eating and education regarding this is built in in a practical way. Additional baking projects and other cooking projects take place regularly at Headway House, and Headway also run a Pop-Up Restaurant project where Members are supported to work with professional chefs to run a restaurant at the centre for an evening for the general public.*

*HEL Occupational Therapist also supports and advises particular Members around specific difficulties in the Kitchen, for example, cooking using one hand, and HEL Volunteers are offered in-house training in ways to support Members in the kitchen. Rehabilitation is also offered to transfer skills to cooking at home, where possible. HEL staff also make referrals to local Occupational Therapy services, for example the Adult Community Rehabilitation Team.*

***Helpful Ways to Encourage a Healthy Diet:***

- Adequate support to manage cooking and shopping; facilitating active participation where possible, for example through social services funded Support Workers.
- Adequate finances and support to manage budgeting to pay for food, for example, ensuring that Members are receiving the benefits to which they are entitled; ensuring Social Services offer adequate support with financial management either directly or through Support Workers.
- Encouraging participation in Exercise, Gardening and Cooking Projects: at HEL or via MIND or Healthy Living Project. However, many Members require specific help to transfer skills to their home environment, due to their cognitive disability, and many require on-going help, for example through Support Workers.
- Ensuring Members have information about dietary requirements for specific conditions in a format which will promote understanding and recall. This may come from a medical source such as a Dietician. However, in order for some

Members to apply this information, support may need to be on-going, for example, through Support Workers.

### 7) Community and Leisure Activities

***See Cooking, Gardening and Exercise above also.***

Obviously, all Members attend Headway House / Young Person’s Group at Headway East London.

Additional Community Activities attended by Members are:

The Stroke Project: 1

The Stroke Association, Hackney: 1

The Young Stroke Survivors Group: 1 – ‘good company and good for sign-posting’

Bow Belles, Tower Hamlets: 1 - “camaraderie; older age group”

MIND: 2 (including ‘Mindful Yoga’).

Centre for Better Health: 2 - “good value”; includes Maths, English, Martial Arts, Bike fixing, baking, counselling and massage.

St Luke’s Community Centre, Islington: 1 – “cup of tea, Tai Chi; cookery etc.: good value”.

***Barriers***

- Lack of awareness of options –as for Therapies above
- Lack of transport including lack of availability of family / Support Workers to accompany there and back.
- Variable ability to cope with the effects of brain injury; particularly for Members with more severe cognitive and behavioural issues, as limited 1:1 support available as part of the services.
- Limited availability of family / Support Workers to give 1:1 support in activities where necessary.

***Helpful Strategies***

- Members who mentioned and enjoyed these activities were typically more cognitively and socially able and were more independent with mobility and use of transport.
- Otherwise those accessing the services had adequate support in setting up transport or supporting them on the journeys.
- The low cost was identified as a positive factor for all the services listed.

***Headway House / Young Persons Group:***

Members reported engaging and developing skills through Discussion Groups, the Women's group, games, art, music, IT including opportunities to blog, Reading Group, outings and relaxation. Members have taken opportunities to raise awareness about brain injury through contributing to Art Exhibitions, Pop-Up Restaurants, talks and training for professionals and students and working on the Life Stories project for the website. Peer support is identified as a key element:

"I like meeting people there and doing things. Otherwise I'd just be sitting at home – the kids at school, my husband at work. I'd be low and bored."

"Sociable"; "friendship";

"Good for my health – like it's normal here. You don't see anyone on bad form. It's like you're going out of a bubble into something normal."

"Enjoy the outings; encouraged to use my brain through crosswords and quizzes; stimulation; creativity; art." "They understand my problems… I don't have to explain all the time because my brain gets confused; goes blank; gets periods when I can't think straight."

"He loves it. He jokes with people. Otherwise we're with each other 24 hours a day. He needs everything done for him. I need a break from him and he needs a break from me."

"I really enjoy it. It's some time away to meet peers; friends. I learn from their experience – how their coping."

"I'm trying to find a quality of life without feeling guilty about it after my brain injury. It's difficult as there's an issue of feeling I'm not contributing or an active citizen. Headway challenges those stereotypes and I know I can draw on expertise."

"Really like it – be comfortable; people are understanding. If I get stuck it's not a problem here. I'd never done art before – it's calming."

"Fun, laughter, camaraderie; views and ideas exchange; out of the four walls of the house; friendship; chat. I'm happy so I'm healthier."

### 8) Transport: use, barriers and strategies.

Hospital Transport: 2. 1 Member reported positive experiences of this for accessing hospital appointments. Another reported "late".

Dial-a-Ride: 2 - Members reported using this.

However, Members reported mixed experiences. 2 reported that they were “useless” as they “never turned up on time and booking journeys took time.” Another Member reported no problems. However, shortly after that, his key worker reported that it typically turned up between an hour and an hour and a half late to take him home from Headway House. Another reported it was ‘very reliable’ for accessing Ability Bow x2/week.

Taxi Cards: 7 Members reported using this. One Member described it as more convenient than Dial a Ride but was unaware that there was a limit to the annual number of uses / budget.

Freedom Pass: 12 Members used this.

Members were very positive about their Freedom Passes. However, one Member reported that bus drivers were “useless” at enforcing the need for people with pushchairs to make space for wheelchair users. Another reported finding it “embarrassing” when there are difficulties with the bus ramp, but found London Transport “all right”.

Another reported wanting a Freedom Pass when asked, but required prompting and support from his key worker to apply. Key workers also often need to support people to replace these as Members lose them.

The Carer reported that whilst her husband had free travel using the Pass, she had to pay to accompany him on journeys, which limited their community access. A Support Worker who works with a Member who is a wheelchair user (Tower Hamlets resident) recently reported that the bus drivers’ behaviour has changed so he is no longer allowed to travel for free when pushing the Member’s wheelchair.

Own car: 1 Member reported driving themselves.

2 Members reported being driven to appointments and activities by family members in private cars; one obtained via Motability, which she reported was “very helpful”.

Members who are not able to travel to and from Headway House independently access Headway as follows:

Dial a Ride: 1; driven by family: 2; drives self: 1;

accompanied on public transport: 2 (1 by family member, 1 by paid carer);

transport used by Headway and paid for by Social Services: 2

***Barriers***

- Need for adequate support with application forms
- Poor reliability of Dial a Ride + difficulty setting up repeated journeys
- Crowded nature of public transport with variable physical accessibility

- Need for support due to physical disability e.g. pushing a wheelchair but also due to cognitive and communication disability such as difficulty planning and recalling journeys, disorientation, difficulty asking for directions and help.
- Costs e.g. of longer taxi rides; costs of accompanying carers
- Limits on Taxi card use.
- Failure of Social Services to cover transport costs where necessary, e.g. to support attendance of Headway House.

### *Helpful Strategies*

- Freedom passes
- Adequate support and advocacy, e.g. via Support Work
- Opportunities to practice routine journeys and trial strategies e.g. with community therapists and rehabilitation assistants
- Provision of specific low cost transport to access specific groups and activities.

## 9) Other

As mentioned through the report, advocacy is essential for most Members. It had been important to offer support with accessing and challenging social services, getting and keeping benefits, coping with debt and getting appropriate housing.

The specific Advice and Advocacy services accessed by Members and the Carer are:

Floating Support Worker: 1

Family Action: 1

Family Mosaic: 1

RNIB: 1

HEL Advice and Advocacy Worker: 6 - "I need a specialist brain injury advocate."

The Advice and Advocacy Worker supports key workers with Members' issues, as does the Family Support Worker. In addition, the HEL Therapists and Clinical Lead liaise, refer and signpost to health and leisure services as well as contributing to assessments for Social Services funding.

**Report Compiled by Amanda D'Souza   Clinical Lead, Headway East London**

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