



## Fund for Health



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# Fund for Health 2014

## What is this fund about?

The Fund for Health is a joint funding programme by Healthwatch Hackney and NHS City and Hackney Clinical Commissioning Group (CCG). The fund was set up to enable the voices of those who are often not heard directly to be taken into consideration by policy makers and health service providers. The aim was to fund a range of community research projects delivered by local community and voluntary sector organisations and focus on getting people's views about using health services.

## We wanted to hear from...

In order to improve services in the future, it is important to understand how people experience using them now. We were particularly interested in hearing from people who don't speak English as a first language, young people, those with learning disabilities or low literacy skills as well as any other excluded groups. Organisations carrying out the research were also asked to gather views from people who use health services often, such as those with long term conditions, mental health problems, disabled people and those who are caring for others.

## What did we want to find out?

Healthwatch consulted with the public to set its priorities for the year, and 2 of these were agreed with the CCG to be priorities for this fund. We set out to find out about:

### Barriers to Healthcare

The aim was to find out about how people from vulnerable and hard to reach groups experience access to health care and health information. What are the things that may prevent people from getting the care they need? What are the main sources of health information for people? What other issues are there? How can signposting be improved?

## Patient Centred Care

The aim was to find out how people who use a wide range of health services or use them more often than others, experience health services. What works well and what doesn't? How could the services be more patient centred and holistic? How could the services better support those who would like to manage their own conditions?

## What were the outcomes?

This leaflet presents a brief summary of the projects delivered by local community groups and their recommendations for improvements. A more detailed report on the research projects will be produced following discussions with commissioners from NHS and the local authority. If you would like to find out further information the full reports are available from Healthwatch Hackney: 020 7923 8188 – English / 020 7923 8185 – Turkish or by emailing [liz@healthwatchhackney.co.uk](mailto:liz@healthwatchhackney.co.uk)

## What happens next?

The findings and recommendations from the projects will be shared with the commissioners, policy teams and decision makers including NHS City and Hackney Clinical Commissioning Group, London Borough of Hackney and NHS England who commission local health and social care services. A public event will take place on October 21st 2014 to bring together the organisations who have been delivering the projects, members of public and patient groups, providers and commissioners to discuss how to best address the recommendations and use the findings to improve health and social care services for vulnerable groups.

# Fund for Health Projects

## African Community School



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### Project Summary

This project focused on parents living in long term domestic violence relationships and looked at the barriers to health and social care experienced by those affected by domestic violence. Domestic violence training and video screenings were offered to each organisation to facilitate discussion. Interviews were conducted with the police, adult social care, and children's social care, and focus groups were held with parents from various community organisations.

### Recommendations

#### Signposting

- Domestic violence organisations should have accurate and up to date information about relevant services, for example flyers and leaflets, as well as details of online sources of help and available support.
- All frontline workers and police should have the necessary knowledge to identify people experiencing domestic violence and making necessary referrals, most especially for those with multiple and complex needs.
- GP services should be able to provide information, leaflets and flyers around domestic violence. Surgeries should have health care trainers on site for social prescribing.
- Information leaflets should be available in different languages, Braille and large print.
- There should be access to interpreters and translators especially during out of service hours.

- Leaflets and flyers should have information about disability access, to ensure clients are referred to appropriate agencies that can meet their required needs.

### Resources and services

- Training should be provided to community workers, local organisations and health care workers on domestic violence/ abuse awareness so that they are able to give support and signpost clients to relevant services.
- Community organisations in contact with adults, families and children should have in place policies and procedures statements to reflect domestic violence /abuse.
- Front-line practitioners who provide services to children, young people and families often have to make decisions on sharing information with other practitioners about those they are involved with. This calls for professional judgment on a case-by-case basis. Uncertainty about the legal framework can sometimes hamper effective information sharing.
- As a result organisations dealing with domestic violence clients should maintain appropriate confidentiality at all times.
- To create hubs for surgeries where health care and domestic violence professionals can provide information, advice and support within a relaxed environment.
- More in-depth training of domestic violence and work of MARAC.

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- Funding to provide support for clients who will experience difficulties in travelling long distance due to signposting.
  - To provide awareness training specifically targeting men on the issue of domestic violence.
  - Professionals working with clients should carry out an initial assessment to identify the needs of adults with multiple and complex issues.
  - To make available financial, housing and refuge support to people experiencing domestic violence/ abuse.
  - Police should be offered more training on how not to be judgemental or prejudiced and to be sensitive when dealing with domestic violence victims.
  - Domestic violence victims to be empowered to go back to work and resume normality building up their self-esteem and confidence.
  - Domestic violence is a serious issue which affects approximately 37% adults and young people in the community. The effect of this abuse can lead to mental illness or other health related issues and in some situations, devastating consequences such as suicide.

### Individuals

- Individuals want to feel listened to and need to feel like professionals empathise with them and believe their stories.
- Individuals would like to have access to a safe support network for women and children
- Women do not want to be a burden to the social system and want to feel empowered in terms of financial independence, training, access to employment and new skills
- GPs need to be responsive to women who are asking for help

## Hackney Disability BackUp



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### Project Summary

This project took place within the framework of Hackney Disability BackUp (DBU), a Forum which aims to voice the concerns of disabled people in Hackney on matters that impact on them, particularly with regard to services provided by the statutory sector, and aims to empower disabled people, particularly through the promotion of the Social Model of Disability. Age UK East London has provided administrative support for DBU since July 2011.

A small group of volunteers were recruited to undergo training in how to conduct an accessibility audit of public buildings. Those who completed the training were invited to carry out a pilot audit, on the ground floor of St Leonards Hospital, where a wide range of community health services are based. Once completed, the audit report will be made available to Healthwatch Hackney and the management of the said building in the hope that this will lead to necessary adjustments wherever possible and better practice in future. The ultimate goal of this pilot project is to create the basis of an Access Group in Hackney, similar to the long-standing and active groups which already exist in the City and 12 other London boroughs.

### Recommendations

That Hackney establishes an Access Group, with aims and objectives, a mission statement and a long-term business plan.

That the Group aims:

- to examine services and facilities in Hackney, auditing their accessibility and usability against predetermined criteria
- to identify physical barriers and consider means of eliminating or mitigating them
- to be formally recognised by key agencies such as NHS Property Services, London Borough of Hackney, Homerton University Hospital, East London NHS Foundation Trust and forge effective working relationships with their respective facilities managers and staff
- to be credible with disabled people and DPULO groups in Hackney
- to be committed to training and development of 'professional' standards
- to be established as a formal body or Group (either as a separate organisation or as a sub-group of an existing organisation)

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**That the Group has policies and procedures in place, which include:**

- membership and recruitment procedures/ contracts
- procedures for monitoring and evaluating volunteer tasks
- equal opportunities, health and safety and other policy statements such as a confidentiality
- a volunteering policy statement (members are likely to be entering and inspecting buildings where vulnerable people are being treated. Therefore the necessary legal procedures, including Disclosure and Barring Checks should be undertaken.)
- a disciplinary and grievance procedure should be in place
- guidance on participation in meetings, particularly anything such as management committee meetings, should be given.

## Alevi Cultural Centre and Halkevi Community Centre



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### Project Summary

In most healthcare systems, it is acknowledged that Turkish and Kurdish speaking communities have until now experienced poorer health and barriers to accessing certain services. This research project looked at access to health care by Turkish and Kurdish speaking communities in London Borough of Hackney. Research was focused on the process of care, and the quality of care received as well as the uptake of GPs, dentist and Hospital services. In total 150 people over 50 years old took part in the research.

### Recommendations

- Patients need to be informed about the services which are available to them, such as those provided by local authorities, GPs and hospitals. Although people are aware of these services, they do not know how to access them and need more information explaining this. For example, the survey suggests that 85% of the participants are not aware of how to access care through local authorities. They do not know how and where to get information. Another major problem the patients faced was the lack of language support. Although the interpreters are good in helping out there are not enough to provide the service. Sufficient and timely interpretation services needed.
- As a result patients have to wait long periods in order to be seen. If the translation service is not available then the patients are not informed and advised about their issues and therefore either have to wait or take their children along to interpret.

This leads to many problems because service users don't want their children knowing about their issues so the children are not emotionally affected.

- Waiting time for elderly patients should be limited to 10 minutes or maybe similar age groups should be seen on same day. An example of this is the 60+ patient session arrangement where GPs give enough time to elderly.
- Some patients feel they are not listened to by GPs and do not forward them to the hospital by giving basic diagnosis such as stress.
- The survey implies that the participants are unsatisfied about the appointment system. They are forced to call in on specific days in order to be put in a queue, meaning that they cannot get an appointment the same day. They are not able to explain how urgent their condition is over the phone and therefore need a phone line with a Turkish speaker. Some of them need to wake up very early, such as 7.30am in order to be at the GP for 8am to get an appointment.
- 31.25% of the participants are unsatisfied with the doctors decisions because they are not involved enough and the ones that are satisfied are not able to fully understand or express themselves.
- A majority of service users are confident enough to make a complaint but do not know the procedures in order to take further action.
- Increased awareness of dental services needed, nearly half of the people surveyed do not use dental services



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## Choice in Hackney



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### Project Summary

Choice in Hackney organised a large event for disabled people in Hackney with two goals. The first was to better understand the barriers to health and social care services and self-directed support via a series of workshops at the event run in conjunction with partner organisations. Additionally, they hoped to influence and inform local councillors so they could develop a better understanding of the social model of disability and the barriers disabled people face in this borough. This event encompassed people with learning disabilities and issues of mental health and had approximately 200 attendees.

### Recommendations

- Disabled people's user led and user voice groups to meet regularly
- Signs to be put up in pharmacies to indicate if there is private space to talk
- Improved communication between GP out of hours and A+E
- More support and funding for local user group run events
- Fact sheet of 'top tips' to be written by service users explaining rights to assessment and the processes involved. To be disseminated by health and wellbeing board partners
- LBH to undertake a task and finish review of iCare involving Health Watch Hackney and user groups
- Adult Social Care and disabled people's representatives to meet and look at alternatives names to the term 'social care'
- Time spent with GP's at appointments need to be more flexible
- Commitment to embedding co-production as part of the Better Care Programme by Health and Wellbeing Board Partners and user led/voice groups
- A strategy to be co-produced to ensure that people with no communication are able to be heard at assessment stage and at commissioning stage.
- Training for all staff in contact with the public on what organisations are out there and how to find out about them
- Quality assured information points at universal services and VCS organisations – with informed signposting being an integral part of job descriptions/ funding agreements.
- Accessible information co-produced across the health & wellbeing board partners designed around users' needs rather than services available.
- Strategy for wider staff training developed across the health & wellbeing partnership so training courses encourage integration.
- Disabled people need to be better represented in the Local Authority at Councillor level
- Ensure the venue is accessible – Hilman Street is not accessible to everyone.

- Parking is a major issue in the borough which needs looking at
- Access forum needed to look at all of these issues
- Lack of transparency and staff training in the care assessment process
- Clear information needed for people to make more informed choices
- More support and signposting needed for those with low and medium needs

## City and Hackney Mind



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### Project Summary

There is a substantial population of people identifying as lesbian, gay, bisexual and/or transgender living in the City and Hackney (estimated between 4 to 10 per cent of residents). Yet surveys, interviews and focus groups aimed at LGBT communities and health and social care professionals indicate significant obstacles to a good experience of health and social care for the LGBT population. City and Hackney Mind's research project finds a lack of targeted services for LGBT people and reported discrimination, homophobia or insensitive behaviour from frontline staff in a health and/or social care setting, leaving service users feeling embarrassed or alienated. Participants ranked GPs as the least likely group that LGBT populations in the City and Hackney would want to disclose their sexual orientation or gender identity. Respondents were more comfortable in disclosing this information to sexual health services or LGBT specific services, and not necessarily in the boroughs of City and Hackney.

### Recommendations

#### Providing staff with specific training

Respondents have indicated a number of areas in which training should be provided for health care practitioners, including senior frontline staff. In this regard, therefore:

- it is important to improve practitioners' knowledge on mental health issues, as LGBT respondents currently feel that healthcare personnel are not well equipped to address mental health difficulties and how these may or may not interact with

issues related to their gender identity or sexual orientation, for example in experiencing discrimination or isolation. staff should also receive more training on specific health care issues for LGBT persons in relation to sexual health. Creating a more inclusive environment has to be matched, in fact, with more specific medical preparation on how to respond to the needs of the LGBT population on matters of sex, sexuality and reproduction;

- more attention should also be paid in the context of floating support and social care, where respondents report a lack of awareness on specific LGBT health care needs. Practitioners should be equipped to take into account patients' sexual orientation and/or gender identity when making their interventions.
- Transgender-specific health care is another important area where targeted e training should be provided to health care practitioners. Practitioners should be trained in order to avoid making assumptions on their patient's gender identity, as well as addressing the physical and psychological well-being of their patients or clients as a whole. patients as a whole.

### **Creating a safe environment for lgbt patients**

Discrimination or prejudice is perceived by the majority of respondents to the survey as a major issue that personally affects them. There is an opportunity for health and social care settings to become sites where LGBT communities are able to overcome feelings of vulnerability and stigma associated with their sexual orientation and gender identity for a meaningful improvement to wellbeing.

- Health and social care services should provide inclusive material (media, booklets, leaflets) on health that encompass various sexual orientations, gender identities and forms of gender expression;
- Health and social care services should include information on mental health care support available when LGBT patients express distress and/or discomfort associated with social stigma and other discriminatory experiences.

### **Promoting a clear policy on confidentiality**

While a confidentiality policy will be in place in many settings, the results of this research indicate that individuals are not always sure about whether this requirement is met by their health care providers. Some respondents gave examples of confidentiality being breached. Providers are, therefore, encouraged to:

- put in practice and raise awareness of a written policy on confidentiality which ensures that the privacy of all patients is guaranteed at all stages;
- make confidentiality on issues relating to sexual orientation and gender identity part of their ethical standards;
- ensure that staff handle information in a sensitive and adequate way (e.g. when booking appointments, when interacting with patients in front of the general audience, when referring patients to other specialists).

### **Adopting sensitive and inclusive language and practice**

Many respondents report that practitioners demonstrate a significant lack of awareness to address patients' sexual orientation and gender identity in an inclusive and respectful way. Widespread assumptions on these issues are seen by many as affecting the quality of their health care, thus reducing satisfaction with the service and engendering mistrust in health care practitioners. It is recommended, therefore, that health care practitioners should:

- at all time abstain from making assumptions on patients' sexual orientation and/or gender identity (e.g. asking questions that do not adopt heterosexuality as a standard);
- Refrain from all comments or behaviours that could offend or intimidate the patient in relation to the disclosure of sensitive information concerning their sexual orientation and/or gender identity;
- provide LGBT patients with the same preventive care offered to heterosexual and cisgendered patients, avoiding assumptions about sexual practices/behaviours (e.g. provide smear tests to lesbian women and trans men; STIs testing irrespective of the patients partner's gender).

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## Core Arts



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### Project Summary

The aim of this project was to provide case studies of the experience of applying for a personal budget/ FACS assessment. This information was gathered via interviews and an event for discussion and debate. The report highlights some of the barriers in the current system and proposes recommendations from service users. This is relevant prior to the launch of the new Mental Health Network where FACS eligibility will determine eligibility of component 1 or 2 of the network.

### Recommendations

- Alternative funding for inpatients to access services/resources as part of their treatment plan and for the process to be immediate and uncomplicated
- Training for OTs and Staff nurses on personal budgets and support planning in the community
- Clarity needed on FACS eligibility for service providers and NHS/LBH practitioners so they are able to better support clients on adult social care requirements and how it affects them.
- A clearer process i.e. a named person who is responsible and better promotion of the brokerage service.
- Existing online information pages need development
- Development of a more proactive approach around the application process, current process is reactive, i.e. Care co-ordinators state Core Arts should let them know when an application is to be made or when block funding expires
- More Individualised support plans (format)
- Training for support care coordinators and staff to build their confidence in supporting people to come up with more creative ways of using resources. Senior management support for this approach
- Access to stories and case studies which show how things can be done differently
- Support plans should focus on what is important to the person
- Outcome-focused support planning
- Resources for peer support to enable people to benefit from the experiences of others
- More wide ranging information about local activities and services beyond health and social care
- Train care workers and CMH staff to not only process the paper work effectively but also offer choice and information
- Specialist team to support client and care coordinator with assessments and applications
- Development of an ethos of individualised support planning reflecting a personalised recovery orientated approach from the care team
- Development of user led organisations to provide support, advice, guidance and support
- Ear mark resources for support planning and brokerage including advice, training and support for those in support planning or brokerage roles

- Support planning which enables people to have a choice on who assists them
- Range of options to be made available so people can choose ways to take control that suits them
- Learning from experience the right balance between level of detail and time taken develop a support plan
- Risk enablement as a core part of the self-directed support process with a shared adult personalisation and safeguarding framework to support this
- When putting a support plan together, individuals to be encouraged to do as much for themselves as possible and take account of existing networks of support
- Good communication upon completion of the support plan on what people should expect to happen next and how long it will take
- Goal orientated planning and discussions with care coordinator
- Personal budgets should be time framed to offer a sense of opportunity but should not be used as a punitive measure
- Greater role for peer representatives to give examples of how their personal budgets supported them to improved mental health and self-management skills
- Indicative budget should be decided at discharge
- Need for a holistic assessment at discharge including housing, debts, responsibilities, medication, and use of time social networks. Patients to play a larger role in CPA discharge planning
- Patients to have forward planning relapse plans in place

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## Derman



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### Project Summary

This research looked at the impact of language barriers on health care access and quality of care in the Turkish, Kurdish and Turkish Cypriot communities in Hackney. The focus was on the effects of language barriers on patient access and how access to health and social care services could be improved.

### Recommendations

- Language barrier an issue and can affect the quality of service including communication and adherence to treatment. It can also result in delays in utilising services and inability to share concerns with GP/other professional as well as other issues.
- Interpretation should be available when people need it. Currently people experience long waits due to lack of interpretation services.
- Need for interpreters to have a level of understanding of health issues including basic medical language and the services available.
- Literacy is an issue in the community, so a more visual approach to health care literature is needed
- More accessible ESOL classes
- Female interpreters to be made available for female service users
- Interpretation is not always the best option – people prefer to receive care in their own language, in particular for psychological services including counselling. Training more Turkish speaking therapists and psychologists would help in this. Collaboration between NHS & community organisations: joint working between NHS mental health organisations and community groups, NHS organisations to seek advice around how emotional distress, dementia or physical health are talked about within community so that more meaningful language can be communicated.
- Needs assessment: carry out needs assessments and more information on what services providers can and cannot provide; encourage patients to say when their needs are not met by doing satisfaction surveys and focus groups.

## Hackney Chinese Community Services



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### Project Summary

The research looked at how Chinese people with mental health problems and isolated older Chinese people with poor educational backgrounds experience barriers to healthcare.

### Recommendations

#### Increased opportunities for staying healthy

- Exercise classes such as Yoga classes, Tai Chi classes and walking group
- Stress and relaxation workshops
- Art workshops
- Health talks and events
- Cultural events
- Group activities
- Home visits
- ESOL classes

#### Culturally sensitive services where people can

- speak to the tutor and the learners in their own language
- give comments to the management if necessary for any possible project improvement in their own language
- feel that they have the sense of belonging
- People don't mind visiting other community groups occasionally with the support of the Chinese community project workers and other Chinese project users.
- Package services are provided in the organisation such as health advocate services, welfare advice

service, luncheon club, events, classes and mental health support services. It is a kind of one stop shop which they can access to the right services in one single location. However, they are also given full support to use other mainstream services in Hackney when necessary.

#### Increased awareness of mental health services

- The Chinese community in Hackney have relatively poor knowledge about Mental health issues and do not aware of mental health issues. They do not aware of different kind of mental health and have a lot of misconception on mental health illness.
- The Chinese who live with a mental health problem or are developing one try to keep their feelings hidden because they are afraid of other people's reactions.
- Addressing the issue of gambling where it is identified as a problem
- Gambling is a very serious issue in the Chinese community. We had interviewed 852 Chinese in 2013 randomly selected from our Centre membership database, Chinese school enrolment, BT phone registry and on the high streets of Hackney and Chinatown through telephone or face to face. 75% of our interviewers admitted that they are addicted in gambling.
- Chinese speaking debt advice service to give direct support on financial management
- Chinese speaking Gamble care awareness workshops to make them aware of sensible and compulsive gambling.



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## Hackney People First



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### Project Summary

This user-led programme looked at barriers to mental health services for people with a learning disability. People with a learning disability are often excluded due to the inaccessibility of information, both written and verbal, and so are prevented from giving their views and opinions about important aspects to do with their health needs. By carrying out interviews in an accessible way, using easy-read, objects of reference, and language that is jargon-free, they have been able to voice their concerns.

- Carry out a Mystery Shopper exercise of Mental Health services
- Promote Counselling services
- Make sure there is easy read information of mental health services available in community settings, such as GP Practices and Libraries

### Recommendations

- Train staff that work in Mental Health services to help them better understand the needs of people with a dual-diagnosis
- Support workers should receive training so that they are made more aware of mental health issues and of what is out there to help those they support get their mental health needs met
- Provide opportunities to help people be more active in body and mind e.g. by joining a drama group
- Help people get what they need. Have better signposting to help people get their mental health needs met
- Have conferences to promote awareness of mental health services for people with a learning disability and mental health needs
- Find out what people's experiences are of being in mental health hospitals, and of using mental health services out in the community

## Headway East London



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### Project Summary

Headway worked with their existing client group of adults with acquired brain injuries. Brain injured people can be very difficult to engage due to the complex range of cognitive, emotional and behavioural difficulties – brain injury is often referred to as the ‘hidden disability’. As a result, they find accessing support and services difficult and their voices are often not heard.

### Recommendations

- Improved communication and coordination between health and social services is essential. The Headway East London Community believes 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 a 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.

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- 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.

## Interlink



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### Project Summary

Interlink gathered information about the access of Charedi children and young people to child health and development services, particularly addressing themes relating to children who are failing to thrive. Despite investment there are still health inequalities (for example vaccination levels), so we wanted to look at child mental health, physical development, and speech and language development. The information was gathered via questionnaires given with 1 to 1 assistance.

### Recommendations

We have sought to gather information about access of Charedi children and young people to child health and development services. As the number of Charedi children in Hackney grows, efforts have been made in some service areas to promote access for a group that historically are poor users of public services. We have looked at child mental health, and the barriers to physical development, speech and language development and occupational therapy. We have come out with recommendations for specific services as well as overarching themes that cut across all services.

### CAMHS – within ARK and independent

- Sometimes children who come to be assessed for an emotional problem are sent away to receive a cognitive assessment by an educational psychologist first. Parents need to pay for this costly assessment privately. CAMHS should offer the cognitive assessments, where indicated, alongside emotional problems, to prevent unnecessary delays and keep the child on the system.

- CAMHS outreach support is very popular. Making this a regular feature in the Charedi community in an uninhibited setting will help overcome the stigma associated with accessing CAMHS.
- Speech and language service
- Therapy provision should incorporate Yiddish-speaking therapists familiar with Charedi cultural norms and school setup to improve therapy outcomes.
- A thorough assessment process for the under – 5's, with detailed recommendations for parents and carers, will allow children with SLC difficulties to be adequately supported at an early stage. Too many are screened assessed and dismissed.

### Occupational therapy service

- Therapy goals tend to be focused exclusively on basic motor skills such as walking, dressing/ undressing, cutting and handwriting. There is a need for a fully equipped sensory room to enable children with the full range of sensory problems to improve sensory integration and sensory issues.

### Physiotherapy service

- A closer working relationship with teachers and school staff to guide them on supporting a child with physical needs will ensure that input is multi-pronged and progress is carried over across the board.

### Hearing / vision service

- There is great demand and enthusiasm for a hearing and vision screening service to be delivered at Charedi schools. Uptake of such a service is predicted to be very high, if not complete.

### Obesity prevention services

- Some schools also expressed an interest in a height and weight measurement service and guidance on developing their own obesity reducing programmes at school in line with the National Child Measurement Programme. There would be particular interest in the provision of indoor and outdoor play equipment that encourage healthy exercise.

### EARLY INTERVENTION (CAMHS, SPEECH AND LANGUAGE SERVICES, OCCUPATIONAL THERAPY)

- It is a procrastinated process to get accepted into the service and seen by a **CAMHS** professional. **Children with mild-moderate emotional/mental health needs** should be fast tracked, like the more severe cases, to prevent problems exacerbating.
- A comprehensive assessment package should be drawn up that will accurately diagnose **SLC needs** in Charedi children. Parents have describing accessing the assessment process like a fight for intervention.
- Parents sense a general policy of minimal intervention by the **occupational therapy services**, even where a **child's functional skills** are clearly limited. There needs to be a focus on early intervention, to prevent problems deteriorating and impeding day to day performance. Parents have reported that lack of attention given to problems early on, was often a factor in seeking a Statement of SEN for their child at a later stage.

- We need to simplify referral pathways and entry into services. There should be a stronger focus on providing input for children whose problems are not yet severe, but have the potential to become so if left untreated. Parents' concerns should be taken seriously and addressed within the assessment process.

### QUALITY OF INTERVENTIONS

- High staff turnover and discharge from the CAMHS service before therapy goals have been met may leave the treated child in a worse state.
- We need more intervention sessions with the same therapist to ensure continuity and work towards child SLC goals.
- More intensive therapy input with the same therapist attending sessions, will greatly improve occupational therapy outcomes.
- The physiotherapy service is structured with minimal sessions. More follow-up sessions will ensure that therapy recommendations are implemented appropriately at home and in school.
- The lack of continuity of care has been highlighted in every area where children require intervention. This is primarily because of limited allocation, but will be enhanced by a better understanding of Charedi culture and norms. The small number of sessions and early discharge from services give the feeling that children are not being supported adequately and many development issues escalate as a result.

## Minik Kardes Children's Centre



Tel: 020 79237226 Email: Duygu.Bozkurt@learningtrust.co.uk

### Project Summary

This project worked with Turkish speaking Mothers and pregnant women to look at barriers to accessing antenatal and post natal health services. For the first part, we worked in partnership with NHS professionals at Homerton Hospital and delivered 8 weeklong antenatal sessions. At each session we ran questionnaires about the related health services the women used such as GPs, midwifery, health visitors, health advocacy by volunteer organisations, dentists, hospital emergency units, maternity units, special care baby unit, assisted conception unit, counselling, domestic violence support, and ultrasound scan unit and blood tests to find what works well, what can work better, and what should be changed. For the second part we ran 1 to 1 interviews with the participants of our previous antenatal classes in order to find out about their experience with health services.

### Recommendations

- Review of confidentiality procedures by interpreting service managers who should also ensure compliance, miscarriages and ERP operations should be kept strictly confidential. Interpreters should be present at all times especially during emergencies, not just during booked appointments
- There should be more support for immigrant families newly arrived in UK in order to inform and direct them to available services.
- Partners should be encouraged to attend antenatal appointments
- Training for all frontline staff on domestic violence to provide info about domestic violence support to all pregnant women
- Antenatal sessions should be compulsory and be delivered in partnership with culturally sensitive community organisations, they should be available for all and be promoted in the wider community

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## Mobile Repair Service



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### Project Summary

This project focused on older people (+55) living in Hackney with a hoarding condition. The research aimed to quantify the impact on health and wellbeing of residents who hoard. We carried out data analysis of client information, a focus group and 3 in depth interviews considering the potential impact that hoarding has on a sample of this population.

### Recommendations

For the individual who recognises their hoarding condition

- Clear pathways to access support including first points of contact, and flexibility within support options to meet personal needs must be developed and designed.
- Information and ease of access to financial advice relevant to purchasing appropriate services to manage their condition (direct payments / grants /brokerage support) must be developed and provided.

### For health and social services in the borough of Hackney

- A nominated lead coordinator to identify and manage multi-agency support for individual support needs must be identified and appointed.
- Awareness campaign within support services (health and social care) and the borough to be launched and promoted as soon as possible.

- Development of a training programme to provide front-line staff with the skill-set to respond appropriately and sensitively to the needs of the individual.

### For the Borough of Hackney

- Design, produce and commit to a hoarding protocol for the borough which is user facing and lead by the client group, and respects the autonomy, dignity and choice of people with a hoarding condition.

## Peter Bedford Housing Association



Tel: 020 7226 6074 Email: clare.norton@peterbedford.org.uk

### Project Summary

This project focuses on the homeless and vulnerable adults in Hackney. They are a small specialist supported housing provider in the borough with approximately 130 tenants. They house vulnerable adults who have learning difficulties, mental health needs, ex-offenders and those with substance use difficulties. The project used a survey and focus groups across the homeless pathway and with their recently homeless tenants to identify barriers to accessing health and social care services.

### Recommendations

- **Local housing providers and commissioners should work together to develop a service that streams health and social care information on digital screens where homeless people live or congregate.**

Such a service could be integrated with and use existing content where it has been developed (e.g. for GP practices). Digital screens could be placed in reception areas of housing associations, hostels, local housing offices and Walk-In centres such as Greenhouse.

- **There should be an awareness raising and information campaign to promote iCare and NHS Choices across the housing and homelessness sector in City of London and Hackney.**

The campaign should target both services users and support staff.

- **The potential for developing digital interactive health and social care information points or hubs at venues across the housing and homelessness sector should be explored.**

This recommendation will also support take up of services such as iCare. Service users will need access to computers and other hand held devices to be able to search for information online. As this, and other, research shows many homeless and vulnerable services users are not online or lack the necessary skills. Such an approach needs to be combined with training in basic online skills.

There is considerable synergy to be gained in making it easy for service users to search for health and social care services online not least in developing their skills and independence. This recommendation should be aligned with existing City and Hackney wide digital inclusion strategies.

- **Explore further how peer and other support could be provided to support those who are on waiting lists for treatment or appointments for mental health services.**

This could be undertaken through the Integrated Mental Health Network and the new Service User Led Involvement Network.



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- **There should be a commitment to a person centred approach to the delivery of health and social care services to homeless and vulnerable adults and attendant communication strategies.**

Such an approach will encourage help seeking behaviours. As the Health Foundation states adoption of a person centred approach requires a culture change amongst staff who may need further training.

- **Further research should be undertaken into the extent of abstinence groups that are linked to health and well-being activities across City and Hackney and whether more provision and/or better communication is needed.**

Not wishing to mix with service users who were using drugs or alcohol was cited as a barrier to taking up activities by service users who are in recovery. St Mungos have recently re-started their Sober Saturday group and Lifeline also run some activities that require 24 hour abstinence.

- **Service providers need to do more to promote the benefits of physical activity to homeless and vulnerable adults and to make access to such services easier.**

Suggestions include the provision of free or low-cost memberships of fitness centres and special opening times or slots at leisure centres and facilitated groups such as swimming groups.

- **City and Hackney Clinical Commissioning Group and partners should implement Living Well for Longer: National Support for Local Action to Reduce Premature Avoidable Mortality (Secretary of State for Health 2014) and build on this year's CQUIN incentive targets to support physical health for people with mental health problems.**

As the Call to Action says there are stark inequalities in outcomes across different socio economic groups and Living Well for Longer has particular relevance for the physical health of homeless and vulnerable adults.

- **Commissioners and providers should explore opportunities for synergy and building on the Social Prescribing pilot which is targeted at isolated over 50's and people with diabetes.**

There is cross over between the pilot's target groups and the respondents to this survey (homeless and vulnerable adults). There may be opportunities to improve access to physical and obesity services for homeless and vulnerable adults through the pilot and social prescribing more generally.

## Refugee Workers Cultural Association



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### Project Summary

The project focused on the Turkish and the Kurdish community living in the London Borough of Hackney aged between 18 and 35 and how they experience barriers to health and social care. The aims were

- To learn first contact if young people were sick
- To learn their knowledge about social and health services
- To assess their barrier to reach to social and health services
- To assess their needs to easily reach the services
- To contribute their knowledge about that services with some leaflets and advertisements
- To organise useful opinions

### Recommendations

- Language barriers are the most important issues facing Turkish and Kurdish People accessing social and health services.
  - There should be some opportunities for community centres to provide English language teaching services
  - Health care literature including leaflets in Turkish and Kurdish needed. These should include all significant information about social and health services. The leaflets should be delivered to community groups and GPs and Hospitals.
  - More use should be made of Turkish and Kurdish media here in the UK. Lots of different mediums such as radio, social media, and newspapers can be used to give information about health services.

- Translators sometimes cause problems. Facilitation of translation is poor. We should focus on solving the problem of the quality of translation.
- Another issue is the lack of clear information. Many people haven't got sufficient information about social and health services. As a result, leaflets, community meetings and advertisements are crucial as we suggested above.
  - In particular, information sharing meetings should be organised in schools, colleges, and community centres. This will help service users to reach services and to learn vital information about healthcare issues such as drug usage.
  - Leaflets and advertisements are also significant in trying to solve these problems.
- Many people think that more sports and social activities would help them to live healthier lives and have asked for more opportunities for sports and social activities.
- Youth clubs and community centres are important to service users. People have asked for more facilities and courses about healthy living and wellbeing.
- One of the findings of the report was that 48% of people felt that language was a barrier to accessing health services and 21% felt that discrimination was a barrier, the latter needs further investigation.
- In addition, smoking and in particular the fact that smoking starts at a relatively young age is concerning, more awareness about the negative health effects of smoking and evens to reduce the rate of smoking should be organised.

## Social Action for Health



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### Project Summary

This project worked with people who have little or no access to the internet due to barriers in literacy, language, finance and long term conditions including mental ill health. Using an action research methodology we worked with local people who have been trained as community researchers. Between 70-80 people took e part in the dialogue sessions from the African/Caribbean, White British, Asian and Turkish/Kurdish communities. This project had a 'sense making' stage involving participants from the research to draw out the key findings for the report write up.

### Recommendations

The following recommendations have come from participants' suggestions about how to improve local health services. Additionally, from our experience, we have thought about what responses would work well for local people, having made sense of issues affecting them presently.

#### 1) Awareness raising about how to access GP services

Most participants felt that they never got enough time to spend with their GPs and some were still accessing A and E services due to mistrust of GPs, lack of appointments and negative experiences.

- a) One recommendation would be more awareness around the types of services available such as the 111 out of hours services, requesting a call back from your doctor and when to let GPs know when a medical issue is urgent.

- b) Additionally there is a role here for GP surgeries to improve their relationships within their local community by doing outreach so local people can feel connected to the services and begin to build trust again.

#### 2) Complaints about individual GP surgeries to be followed up

- a) Participants gave feedback from individual surgeries and it would be positive for these complaints to be followed up so that local people can feel that their comments are being listened to and the quality of GP services in the borough is taken seriously.

#### 3) Response by Hackney CCG to the dialogue group

- a) Participants want to hear from Hackney CCG/ Healthwatch about what they plan to do to improve services in the borough. They feel they were open about their experiences but expressed cynicism about any change being possible.

#### 4) Creating social spaces

- a) Health professionals should create social places in schools and estates where they can understand the welfare of local people and how factors such as housing, finance, education and health affect the quality of their lives. From this understanding, health professionals could work positively to reduce health equalities and commission better health services via the Clinical Commissioning Group.

## VLC Community Centre (Centre for Refugees from Vietnam, Laos and Cambodia)



Tel: 020 7739 3650 Email: Vietnamlaocambodia@yahoo.co.uk

### Project Summary

This project targeted the Vietnamese community with the age range of between 45 and 70 in order to establish how they experience barriers to health and social care. Researchers made use of their weekly social and health events and talks, physical exercise sessions to introduce and explain the project to our members as well as to ask for their participation and support. They also relied on their existing contact database to get in touch with Vietnamese residents in the Borough, from whom they may obtain further contacts.

### Recommendations

- Education and training for service users to enable them to access information on all GP services online
- More funding for community centres
- More collaboration between service providers and community centres in order to better engage service users
- More accessible information on all health and social services needed, a large number of respondents for example are aware of the GP appointment service but not NHS Walk in Centres, out of hours services or their right to make an official complaint.
- Translators and interpreters should be more accessible and available, but also the information about them should be made more available and easily accessible through different channels in a bilingual form. A designated number of staff

skilled in a specific language, this “number” would act as an intermediary between the user and the NHS surgery and book an appointment for the patient on their behalf. A widely published designated phone number would certainly benefit many service users who are restricted to communicating in certain languages. Signposting needed on entitlement to dental care, almost all respondents do not know when dental care charges apply.

- Bilingual brochures containing essential information on different health services, these brochures should be designed for different age groups and people of different needs. The age group between 45 and 70 or 80 is a good example.

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## Core Arts



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### Project Summary

206 Hackney resident clients who experience severe mental health issues took part in this project. The information was gathered through an initial survey. Forums were held at Core Arts asking all members who attend over a week to feedback if they wish and to engage those who wouldn't want to engage formally. Each participant was offered the opportunity to feedback further through one to one interviews.

### Recommendations

- The feedback demonstrates a high level of interest and wanting to feedback to the CCG & Healthwatch regarding the experience of care and support services. The member engagement with this research was excellent. Unfortunately, the majority of feedback in the interviews was negative, and interviewees commented on this.
- Services users were mindful that negative feedback is not helpful for managing their care and support (relationships) or beneficial for their well-being however, the opportunity to feedback anonymously (without fear of it effecting current situation) was appreciated.
- There was a lack of understanding from participants regarding what is meant by 'managing you own care'. It was clear that the personalisation agenda and the soon to be introduced new Care Act bill and the changes involved in this significant change in practice has not been understand or cascaded to front-line. Service users are not accessing this information and are not aware of the changes or their rights in line with the agenda.
- Due to the open nature of the survey, and the invitation to fill it in means the cohort of respondents was varied and it is unknown if the demographic is reflective of emotional and mental health service users in Hackney. Likewise, the experiences from the interviewees cannot represent other patient experiences. The themes that arose give more indication of issues experienced across the breadth of care and support.
- The response regarding the role of GP's would suggest that GP's in particular need to ensure they have an awareness of the need and what is available across the sectors to their clients, including information regarding managing own care and the introduction of personal (health) budgets.
- The prevalent discussion regarding benefits, cuts and economic climate is indicative of the concerns and pressures experienced by service users and would suggest there should be an investment in services to support his area. Interviewees highlighted the significant barriers faced in work like activities and the setup of the system (patients would be worse off if they work). Mental health services need to provide opportunities for development and ways to access work however the financial ramification for recovery need to be assessed for long term stable mental health and progression.

- The importance of staff understanding/ communication and approach. A point of concern that would warrant further attention is that a number of service users reported complaints or issues with professionals care relating to respect, knowledge and understanding implying that further work, training and personalised approach should be undertaken with client facing staff. There are high expectations from services users of the care and support they will receive from CMHT/ hospital staff which is contrary to the experience. Awareness of this issue could support patients and staff to discuss limitations of their role and realistic working together.
- Service users were forthcoming in suggesting solutions to the issues or barriers that they faced (including the need for a 'refuge' or overnight support service that is not the hospital for persons who are not managing their symptoms but do not require intervention) which would help them better self-manage.
- It is really encouraging to see the high proportion of those responding to the survey were engaging with a variety of services available in Hackney; despite most of the feedback focusing on statutory services. The feedback regarding voluntary sector services was largely positive. Service users are keen to be part of the running of mental health services and opportunities in this area were discussed by all interviewees.
- The need for advance directives to be discussed and put in place when a patient is well and able to analyse their triggers and risk management regarding the patients view during times of crisis and mental health deterioration to support the clinicians to make decisions in line with the patients wants and to minimize the harm caused (especially if hospitalisation is required)
- The importance of friends and family involvement with support is imperative for holistic support and consistency across various aspects of a person's life, character and interests. The development of support services to include friends and family (especially Carers) in planning and opportunities seems beneficial to the patient.

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## DeafPLUS



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### Project Summary

This project worked with deaf and hard of hearing people in Hackney & City of London. The aim was to understand how the participants experience access and barriers to services and information.

### Recommendations

- All the frontline staff need to have deaf awareness training – How to communicate with deaf service users and understand the need of deaf service users.
- All the service managers must be aware that Healthcare Advocacy does provide British Sign Language Interpreters, not just foreign languages. They must ensure that their staff are aware of this and know the processes involved.
- Do Dentists work with Healthcare Advocacy, as deaf users confirmed that they do not have BSL interpreters for their appointments?
- When providing diagnosis and providing prescriptions, the health care professionals need to make sure the deaf service user fully understands the information and instructions given. Most of the deaf service users have a low level of English. When the interpreter is not present, the information given by the doctor to the patient or lack of information can be detrimental.
- Can GPs and health services provide different modes of communication rather than telephone, as they can only accept phone calls from the public when appointments need to be made? An email or text service needs to be arranged to make booking appointments easier, this also applies to cancelled appointments and also if the patient is running late. Most deaf individuals have smart phones. Once again highlighting that an email or text service will be very beneficial and one that can be set up easily to create an effective way to correspond with the deaf service users

## Interlink



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### Project Summary

This project centred on the experiences of people with long term health conditions in the Charedi community. The project focused on people with mental health problems and people with age related conditions such as dementia, but did not exclude people with other long term conditions. Interlink worked in partnership with 4 member organisations to interview individuals and found the following.

### Recommendations

Many complaints regarding accessing the different services are centred on assessments and the time lag from referral, to assessment, to care package award. There should be a tighter timeframe for referrals, assessments and panel decisions. The current target of 28 days, for completing the process, is clearly not enforced. A community provider for the learning disabled commented that clients “can typically wait between six and ten months for an outcome.” Below are some of the recommendations which would go some way in alleviating these difficulties.

- Improved communication between hospitals and social services, particularly out of borough hospitals. There should be an option to leave messages and for staff to respond promptly. This issue comes up with the learning disabled, patients with dementia, long term conditions and others, who may require reablement or Adult Social Care.
- The experiences of those waiting for assessments for Continuing Care have also been temperamental. Processes should be audited so there is a consistent approach
- Patients applying for any care packages should be given support, rather than feeling that they have to push to make any degree of progress.
- For patients with high level non-nursing needs, Adult Social Care and Continuing Care should carry out a joint assessment and agree a joint care package.
- In cases of sudden deterioration of a patient with a debilitating disease, there should be a system for fast-tracking **reassessments** and out of panel decisions.
- Application process could be simplified.
- Members of the administrative teams which underpin the assessment processes are often lacking basic skills and competences. They should either be skilled up or redeployed.
- Arrangements should be made for care to cover the period between referral and care plan award. By default, it is up to family, relatives, neighbours, friends and community groups to step in the breach. Not everyone has a wide circle of contacts, family or other support and inevitably, there may be patients who may fall through the cracks and whose needs will not be met.



- Reablement services should be improved so that if a patient still requires assistance beyond six weeks, this should happen without a gap. Patients who have reablement packages should be **reassessed** after four weeks, but this seldom happens. An audit of cases would identify this failing. Regular progress reports submitted by providers could also inform these decisions.
- Where an application has been rejected the appeals process should be simplified. One provider was aware of two cases that had gone to appeals and both were successful. Assessments should be carried out with integrity and sensitivity to avoid the need to go through the appeals process. Where patients lack the means to go through legal procedures, their care/ quality of life may be seriously compromised.
- Assessments should be carried out with the patient's needs coming before financial considerations so that they receive adequate care.

## 6.2 Communication

Issues have been identified in communication between services, communicating with patients themselves, as well as communicating information about how services operate.

- Improved communication **between** teams and different providers will give a more joined up and expedient service to the individual. Issues also extend to IT compatibility; it would be helpful if clinicians from different services would be able to access patients' records.
- Improve communication between departments and teams in hospital and community services for more consistent approach and better understanding of the patient.
- Improvements in communication with medical staff and nurses to patients, particularly on mental health wards. This will help overcome the perception that nothing is being done for them.

- Improved communication around services and expectations – taking the time to have these discussions will avoid complaints and misunderstandings and help patients understand and navigate services ultimately saving time and money. This should be part of any consultation with clinicians and therapists, but there may also be a role here for social workers and dementia advisers.
- Regular Multi-disciplinary Team meetings to update on the circumstances of the mental health patient should be held with the patient at the centre. This will ensure effective communication with and about the patient.

## 6.3 Cultural issues

Many a difficult situation can be worked through with a greater understanding of Charedi norms and practices. There are opportunities for attending presentations as well as cultural walking tours. Often it is this context that it is critical for clinicians, therapists and social workers to understand and meet patients' needs. Whilst offering insight into the Charedi community, lessons can be applied to other communities with different nuances.

Specific cultural issues that arise are:

- In end of life situations, especially where there is a terminal diagnosis, care should be taken in how to communicate this with the Charedi patient. The Charedi community puts great emphasis on the sanctity of human life and conveying positive messages to inspire hope and recovery. There is a culture within the NHS and social care of openness and sharing of information with patients which does not sit comfortably with Charedi culture. Often relatives may request that the patient should either not be told, or be protected from the full impact of the diagnosis, which is often disregarded by clinicians. More insightful information in this area, which touches on caring for very sick Charedi patients, attitudes to dying and end of life care, can be found in a comprehensive locally commissioned piece of research .

- There needs to be more flexibility in use of allocated care hours without risk of cuts to hours because tasks do not conform to eligibility criteria of social care. There may be cultural factors which influence how people want or need to use their care hours.
- Statutory Service providers should investigate through training and sensitive discussions how it can enable carers to access support by making it more culturally appropriate.
- Community based support from Charedi organisations forms a critical part of patient care. Charedi providers should be commissioned to deliver services to patients as they can do this within the context and framework of the patients' own faith and culture. This is not to say that Charedi patients should be given anything extra. Rather, greater thought should be given to the importance of commissioning specific Charedi provision alongside general provision, so that Charedi patients are also able to access services.
- The difference is not only in the type of activities, but also in the way they are delivered. Many mainstream activities may be inappropriate for Charedi patients, e.g. a visit to the cinema. This can present quite acutely on mental health wards, e.g. a patient may participate in a "pampering session" when they are quite sick. Looking back once recovered, a patient was horrified to note how 'gaudy' she had allowed herself to be made up.
- Mixed gender activities are not taken up by the Charedi patient. Charedi providers offer single gender programmes in a culturally sensitive environment. Patients may also request a same gender carer.
- Some of the commissioned services have had funding cuts and community providers have had to take difficult decisions around which services to cut. These should be reinstated as they give patients an enhanced quality of life. This should be seen as an extension of the social prescribing

model where patients are offered non clinical interventions which serve to improve their physical and emotional wellbeing especially for the learning disabled and those with long term medical conditions.

- Culturally sensitive training for paranoia support or hearing voices support groups, as well as how to advertise them should be developed with the community.
- There should be more community support for mental health patients immediately after they are discharged from hospital to match demand. Community peer support or similar is critical at a time when patients feel very overwhelmed.

Notwithstanding the crucial role played by Charedi community provision, due to stigma attached to some conditions and to protect privacy, some Charedi patients will opt to attend mainstream support services. This affects children, adolescents and adults. These should be audited in terms of numbers and their accessibility for patient choice.

#### **4. Recommendations for individual providers**

Whilst some changes may not be very difficult to implement, they may require changes in the culture of how services are delivered, and this will need to be cascaded from the top downwards.

##### **7.1 Adult social care**

- There should be consistent arrangements for follow up visits and discussions with social workers and therapists regarding treatment or wellbeing, rather than ad hoc arrangements, e.g. some social workers visit every month, whilst others make no contact for months on end.
- The allocation of a key worker to represent patient's best interest would enhance services and trust.
- Continuity of care would be helped by the same clinician/therapist seeing the patient every time, where possible.

- Care packages should reflect needs of patients with due regard to concepts of autonomy and independence. Half hour slots for the required tasks are not feasible. These slots should be extended to at least an hour, rather than half an hour, and should not be cut down as has been the case in some instances.
- The system for allocating cleaning duties for sick patients needs to be changed. This will avoid the need for Blitz cleaning every time carers or social workers refuse to attend due to the state of the home.
- Direct payments should only be offered if there is confidence that patient can administer well.

### **7.2 Reablement**

- Social workers should be made aware that they can get out of panel authorisation for reablement.
- When service will be working optimally, a review may identify when shorter packages will be adequate.

### **7.3 Mental health**

- Some nurses and junior staff may benefit from customer care training.
- Vulnerable patients should be given senior support to feedback on experiences, good or bad, without risk to service provision.
- More effort should be put in to involving patients in target/goal setting and evaluation.
- Realistic Action Plans should be drawn up to enable efficient and safe Discharges.
- Discharge planning should be improved to avoid readmissions; a peer supporter could visit patients soon after discharge to smooth the home-coming and adjusting. Carer/husband needs sufficient notice and support to manage the entire home situation.
- There needs to be better access to GP's for patients with complex needs especially dementia and long term conditions

### **7.5 General**

- Perhaps there could be a voucher scheme as an alternative means of transport to and from hospital appointments.
- Perhaps there could be a voucher scheme for incontinence pads so that they are better matched to needs of patient, or Incontinence service should provide better quality supplies.
- Information and training should be made available to social workers on a range of issues. These include when out of panel decisions, authorisation for care packages or changes are available, and information about health conditions they will be assessing for.
- Raising awareness of out of hours support available to recently discharged hospital patients and to patients with complex medical needs and their families. They should be given some navigation to understand how the services/teams operate during and out of hours and how to contact them e.g. the District Nursing team can manage some aspects of acute care avoiding the need to go to A&E; the CHUSE GP out of hours service.
- Hospital transport services should be more sensitive to vulnerable patients.

### **7 Good practice examples**

Along the journey of gathering patient stories and experiences, patients, carers and providers praised a number of practices and services. A number of respondents described how the knowledge and treatment/care of a particular clinician/therapist, has resulted in excellent care. There were positive experiences of the Hail specialist carer provision, the EQUIP (Early and Quick Intervention in psychosis) model, the Adult and Community Rehabilitation team and the dental services which were described as excellent. There were also good working examples of joined up work between speech therapy, physiotherapy and dietetics teams which patients found reassuring.

## Minik Kardes Children's Centre



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### Project Summary

This project focused on the Turkish speaking parents of disabled children. We ran 2 focus group meetings at King Henry's Walk Garden where there was a very peaceful and relaxing atmosphere to handle this sensitive process. We had discussions for amending the questionnaire. We also had a couple of interviews for the parents who wanted to share their views in front of others. We ran 13 separate 1 to 1 interviews with carer parents, including one with a father with each interview taking around two hours. The main issues identified in a broader sense were; late diagnosis of disability of the child, shortage of health professionals, failure of health professionals recognising and acting upon domestic violence related cases (i.e. failure to signpost), shortage of referrals to counselling and other specialist services, long waiting lists, language barriers, lack of understanding cultural context (i.e. resulting in failure of engaging male partners in the process), failure to provide information on patient's rights (such as information on PALS), disempowering patients.

### Recommendations

- Disability support services to start at earlier stages of pregnancy.
- Mothers who have knowingly and willingly taken the decision to give birth to a disabled child to be supported at all stages.
- Partners (males) to be encouraged to be involved during the pregnancy health checks and to maintain their support for birth and after care of a disabled child.
- PALS information should be provided to all patients.
- Interpretation services should be improved and interpreters should receive training to have awareness on various working policies and procedures.
- Antenatal screening centres to be given point base ranking according to their accuracy. Scan results should be saved for future investigations and accuracy performance of the centre for the diagnosis afterbirth.
- There should be a support service in place before discharging parents to prepare them emotionally and give them information about where they can seek help.
- Labour rooms to be bigger and more comfortable.
- Ideally each family to have their own room.
- C-section and natural birth mums to be allocated separate rooms.
- Visiting hours to be shorter.
- One person to be allowed to stay with the mother over night after birth.
- More of therapeutic support needed for acceptance of child's disability.
- After diagnose, the child to be provided with one to one rehabilitation education.
- Treatment / rehabilitation research to be developed for autism.
- Hackney Ark should keep up the good practice!

## Volunteer Centre Hackney



Giving is Receiving

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### Project Summary

Using their own "Step Up" project and networking, Volunteer Centre Hackney recruited service users and conducted outreach for a project working with people with long term mental health issues in order to understand their experience of patient centred care. They ran 2 focus groups of 8 – 12, as well as conducted an online survey developed with focus group participants. They also plan to develop conversations from the focus groups using social media.

### Recommendations

- 24 hour crisis service in the community but particularly during n nights and weekends to prevent hospital admission, calling A+E can lead to hospital admission and lacks the care and consistency that can be given through a more personalised service.
- Night and weekend respite to cover the times when people often feel most alone and most vulnerable
- Volunteer visitor service for mental health in patients
- A+ E services should have a psychiatric nurse on duty. Patients in mental crisis have to sit amongst A+E visitors waiting for hours to see a triage who then makes a referral to a psychiatrist as they don't have relevant specialism.
- Patients saying they feel in danger should be listened to at A+E and the patients should not be sent home because they do not display the 'right' symptoms
- Advocacy services in hospital are essential to enable people to articulate what they need including being discharged, e.g. services like that provided by Mind.
- Peer support works very well. Received through Lee House by one service user. Volunteering important as a way to gain structure and regain confidence as recovery improves.
- Structured activities are very important. "Structure is the biggest key to having a more balanced life".
- More information on available services, and easier access to such information. "Found out about most things through word of mouth and on a need to know basis by referrers". "I want to know what's out there".
- Services need to be networked. "St Leonard's staff didn't know about Shoreditch Trust's Healthy Living Centre which is just around the corner". "Services are not joined up. If you want to get stuck in and get structure you have to know about these – it's the first time I'd heard of Lee House. When you're living a chaotic life, the harder it is to engage, the more it puts people off".
- Referral pathway should be more straightforward – e.g. "doctor referred me to C & H Mind where I then was referred to Lee House Voices Group".
- GPs need to improve their understanding of the issues surrounding mental health. Need to get to know their patients' history, build a relationship with that person and be more honest.

- More training for hospital staff working in mental health wards including doctors. Healthcare staff need more compassion and understanding.
  - GPs' need to be more aware of available services.
  - Network GPs and share best practice? "A lot of variation in care and in knowledge".
  - Texting/ reminder service from GPs' about appointments is very helpful.
  - Relationship with pharmacists should be strengthened so as to enable service users to talk about the side effects of medication without needing to go through a GP every time.
  - What about owning your own health data / status like a health certificate?
  - Grant assessment costs should take into account people's income.
  - Involve service users on commissioning panels
  - More capacity for self referrals, not everyone has a care coordinator and once discharged out of the care system there is no opportunity to be referred to a service without being assessed as having relevant need and being reallocated a care package. There should be an option for receiving some services without needing a care coordinator.
  - More money spent on psychotherapy, less on medication. 8 weeks CBT is insufficient and waiting time too long.
  - Treatment is too focused on medication, it should be more holistic –physical and mental wellbeing are too delineated, but often overlap. Should spend money on massage, alternative therapies; more mindfulness teaching sessions.
  - Need to improve Jobcentre Plus advisors' understanding of mental health e.g. having mental health specialists in house within JCP or Work Programme offices. Can the GP help with issues around benefits which can cause so much stress?
  - More help with childcare for working mothers
  - Mentoring
  - Gym/exercise referrals are excellent.
  - Stop with labelling and classification.
  - More employment support available
  - Training around disclosure
  - More 1:1 chats (not necessarily therapy) just to see how people are getting on.
- Potential quick wins:
- Texting/ reminder service from GPs' about appointments.
  - Maintain gym discounts and exercise referrals.
  - Training on disclosure (provided by mental health service providers?)
  - Encourage and support volunteering services.
  - Volunteers to provide 1:1 telephone calls.
  - Provide more information to patients on available services.
  - Ensure all mental health providers and services in the borough know about each other.

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## Positive East



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This research project is yet to take place. See below for a summary of the project.

Over the past two years Positive East has embarked upon an ambitious consultation and outreach programme with African churches across North East London to try and further understand why people in these groups are not accessing existing HIV prevention and testing services. We were spurred to action due to a high level of late diagnoses within the African Community as a whole and because of anecdotal evidence that those attending certain church congregations were more likely to be affected than those in the general community.

We have carried out numerous testing and consultation exercises in churches across the boroughs where we work, including at the Living Flame Baptist Church in Walthamstow for HIV testing week in November 2013; this event received national media coverage by the BBC and others – <http://www.bbc.co.uk/news/uk-england-london-25077217>

We have supported a pastors and community leaders forum setup in Tower Hamlets with regular face to face meetings to further dialogue and understanding around health issues, and in particular HIV, and church congregations. We are planning to launch our own pastors' forum later this year encompassing boroughs across East London, including Hackney. We believe that this is a vital approach in beginning to breakdown entrenched views that foster ignorance and discrimination.

The funding we have received from Healthwatch Hackney will be used to conduct three consultation studies with African churches in Hackney and will be carried out in the winter of 2014/15.

The funding provides an opportunity to gain up to date and relevant information that will inform health care providers and commissioners about what approaches may be needed in developing services and how they can be promoted (if any) in order to ensure that harder to reach groups at risk of HIV are accessing testing services. This information will also allow us to develop further interventions that work with a faith based approach to health.

**For more information**

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Photo of Healthwatch Hackney and CYPFF (Children and Young People Providers' Forum) Speak Up Event, May 2014