**VCS Assembly Meeting Notes**

**Supporting what matters: How can the VCS in Hackney and City enhance care and empower those ageing, living with a disability or long-term condition?**

**26 January 2022. 10am-12pm and 2pm-4pm**

**Morning Session 10am-12pm**

The meeting was opened with music including: Diana Ross ‘Aint No Mountain High Enough’, McFadden and Whitehead ‘Ain’t No Stoppin’ Us Now’, Ben E. King ‘Stand by Me’ and Rudimental ‘Not Giving In’.

**Vanessa Morris (VM), CEO of Mind in the City, Hackney and Waltham Forest**

* Welcomed attendees and explained the importance of everyone feeling included and comfortable throughout the meeting
* The Assembly purpose was outlined; to give the VCS an opportunity to develop the solutions to the community’s problems. This will help make sure that the VCS can fulfil its potential in supporting City and Hackney residents and working with the partners in Health and Social Care system.
* She highlighted the combined power of the VCS to make change and this as a good platform for that
* Structure of morning session will include listening to a poem written for the assembly by one of our VCS network organisations Interlink, then Dr Sandra Husbands, Director of Public Health in City and Hackney and assembly sponsor, will speak about living healthily for longer.
* Outlined the agenda for the morning session and handed over to **Rosemary Jawara (RJ), CEO of Beersheba Living Well** who chaired the morning session

**Sarah Weiss (SW), Policy & Compliance Officer at Interlink** read her poem written specifically for our Assembly (See Appendix 1)

**Dr Sandra Husbands (SH)** (Director of Public Health at London Borough of Hackney) spoke about the important of the number of years we spend in good health. She spoke about how:

* Healthy life expectancy has gone down
* We will have to live and work for longer
* The socio-economic, cultural and environmental conditions that affect our health and ability to lead a healthy life. Important to consider both what affects your health and how your health can affect those conditions.
* The most common causes of disability, disease and death nationally and the main preventable risk factors

**VM** spoke about the 5 ways to wellbeing, a medicated life and living with a hidden disability

* People with severe and injuring mental health issues die on average 20years younger than other people.
* While there have made some improvements, there are still stigmas around what disabilities are and how they fit with society’s assumptions. Living with bi-polar since I was diagnosed at 14 years. The help received was always around the acute stages of illness and never around how to contribute to a life worth living. This progress feels fragile to people with a disability.
* Shared the quote “I am only disability if my needs aren’t met” – highlights how society has a huge impact on how people with a disability live their lives.
* Mental health of people with disabilities is some of the worst affected locally.
* It’s the small little actions in day to day activities that make the biggest difference; connect, be active, take notice, give, share and keep learning.

**Caroline Nelson (CN), Choice in Hackney**, spoke about the needs of the people served by her disabled-people-led, local charity. Speaking as the CEO of choice in Hackney but also as a blind person

* Accessible information; during the pandemic most information was not appropriate for those with additional needs. The movement of GP services from face-to-face has created huge barriers for people living with disabilities.
* Shared a personal example of needing to book a blood test appointment online, this page was not accessible, so could not do this without support from a family member.
* Hate crime; rate for hate crime amongst disabled people quadrupled during the pandemic. Police considered people living with a disability as unreliable witnesses, therefore hate crime statistics nationally are not representative. There is a need for advocacy support for this population.
* Local authorities need to avoid blanket decisions on eligibility criteria for social services.

**Tony Wong (TW), CEO at Hackney CVS** gave an update on progress and outcomes from Assemblies 1 & 2. (Assembly newsletter with highlights in Appendix 2).

* Call to action to be be part of Assembly 3 – **Supporting What Matters** working group (backfill available for time spent)
* Join ongoing co-design work from Racial Equality Assembly
  + Add your training offer to the directory of culturally appropriate VCS trainings available – contact [jessica@hcvs.org.uk](mailto:jessica@hcvs.org.uk)
  + Get in touch if you have something to say in proposal development for positive representation, safe spaces & reducing exclusions
* Look out for future mental health grant funding through HackneyGiving and managed by Mind to be available – timings TBC
* Read HCVS newsletter for updates

Introduction to breakout rooms by **RJ** -

* The aims of the breakouts was to think aspirationally about how to improve the lives of our community members who are older, younger, with learning disabilities, physical disabilities, or long-term conditions. And then to discuss in more detail what this could look like and how the VCS can use its many skills to help. It is for you to be creative and explore what the solutions could be.

Following the 50-minute breakout session, key breakout headlines were fed back to the whole meeting.

**Highlights from morning breakout rooms:**

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| --- | --- | --- |
| Breakout Room | Facilitator | Breakout Headlines |
| **Adults with LD and/or Autism** | Paula Yassine | * **Connection** - Digital Exclusion and Accessibility of information – need face-to-face interaction * **Health** – Isolation/ meeting friends seen as key to health * **Information** – Idea of local Neighbourhood 1 stop shop for information |
| **Children and Families** | David Kingsley | * **Accessibility of Opportunities** – Greater Awareness needed round volunteering and apprenticeship offer * **Empowerment** - How Can VCS Collaborate in Shaping Services * **Connection** – VCS offer to schools round signposting * Importance of early identification of needs * Need for more **culturally aware services** for people living with a disability |
| **Younger Adults** | Yolanda Lear | * Need for Youth Led spaces to help people open-up on emotional impact of long-term conditions and disabilities * Culturally want to be seen as people first and foremost not defined by disability |
| **Older Adults** | Tony Wong | * VCS need greater support to deliver on monitoring and evaluation * Importance of new roles such as social prescribers to act as safety net * Digital Exclusion – pandemic has brought some on board but not all (more training required) * Empowerment – make more use of lived experiences in commissioning of services * Need for greater join up between statutory and VCS services but also uniqueness of VCS needs to be appreciated * Need for support for elderly ending isolation/ shielding to reconnect – community centres * Fear of dying alone and unnoticed |
| **Generalised theme** | - Importance of activities in familiar surroundings – hyperlocal/culturally  - Holding Statutory Partners to account on Care Act and use Care Act to gain funding for holistic approach to care that goes beyond time and task | |

Following the breakout room feedback there was an opportunity for thoughts or comments to be fed to the whole group

* The joy of older people being back in a room taking part in chair-based exercises and social classes that are available very locally to them. This activity empowered them.
* Not only is geographical location important in empowering people to take part in activities it is also important they are delivered by culturally relevant people, so people feel safe and comfortable accessing them. COVID-19 has increased demand and there is a lack of funding available for these types of services
* As we are now moving past the pandemic stage we need to consider how people are supported with re-engaging, particularly older people who need local guidance on re-integration
* On linking statutory services with VCS, funding is rarely continuous. Social care provision via local authorities is limited to a prescribed provision however the Care Act stipulates that local authorities should look at outcomes important to people themselves e.g. engaging in community activities, work employment. Explore opportunity for local authorities to utilise the Care Act to get more funding for VCS services.

**Break for lunch and drop in open networking session**

**Afternoon Session 2pm-4pm**

Welcome and introduction from **VM** and outlined the agenda for the afternoon.

**TW** spoke on the HCVS vision and how it relates to this topic

* Connect Hackney; running since 2015, extended to March ’22. Target has been to understand how loneliness and isolation impact older people. There has been key learning from this project and this will be shared over the next 12 months, watch this space!
* Lunch Clubs; contract has been extended till January 2023. These clubs provide food, activities and connectivity and our important in our communities
* User Survey 2021; currently analysing survey and will share results soon. Key concerns are the economic strain and fuel poverty and the impacts of this on our services and service users
* Moving forward; as an organisation we are considering how we operate in the new hybrid model and how that translates to services and beneficiaries. This is something we will consider with our partners particularly in the context of future business cases and service delivery.

**Sadie King (SK), Neighbourhoods Programme Lead at Homerton University Hospital, NHS Foundation Trust,** spoke about the opportunities in Neighbourhoods for the VCS and on being a Hackney resident.

* Lived in Hackney for 25 years and brings experience of gaps in services; as a mother; neighbour and patient
* Neighbourhoods programme is about integrated care; removing barriers in between services. It is in its 4th year.
* Key priorities; anticipatory care (currently being piloted), community navigation, and reviewing the development of multidisciplinary teams (MDTs) and meetings.
* Anticipatory care – aims to provide preventative early intervention to improve long term health outcomes. VCS has opportunities to support around understanding the culture change, motivations and barriers to people engaging with care earlier and sharing knowledge about cultural barriers to engagement
* MDTs – bringing professionals together to address the needs of people in the community who have complex needs supported by a range of services. Review will explore the wider determinants of health (e.g. debt and housing) and how this impacts health
* The VCS is central to the neighbourhoods plan to understand and address local health inequalities

**Jane Caldwell (JC), CEO at Age UK East London**, spoke on the experience of pensioners in City and Hackney in the pandemic

* When you have met an older person, you have met one older person and its important to remember they have hugely varying needs
* Age UK facilitate older people reference group (7000 members in C&H). When lockdown hit they did a survey on older people’s experiences. JC shared pertinent quote from 1 year ago “the government has not given a tupany toss about older people, ill people, building workers, supermarket workers, transport workers and health care workers […]. To the government, human life is cheap”.
* There is mistrust and powerlessness older people experience, this results in people feeling abandoned. The big question is how communities keep themselves safe moving forward. We need to build back local trust to enable us to support each other.
* JC shared some statements from ‘Thinking of you’ a project with Hackney Pirates where young children sent letters to older people in the pandemic.

**Elspeth Williams (EW),** Founder of Social Eyes 4 Life, Hackney Resident and Public rep spoke about the work of her charity supporting those who are sight impaired but also those living with long term conditions.

* EW shared some examples of how those with visual impairment can be disadvantaged when it comes to emergency situations due to their impairment and the importance of emergency services to consider this
* Zoom as a good tool for inclusion for those with disabilities. Consider hybrid meetings for people with access needs
* Many people with visual impairment have given up on engaging with services
* The importance of being a friendly neighbour; Compassionate Neighbours – a service where people are matched with someone living with a health condition and check in on the phone regularly
* Be considerate of people with additional needs; formatting, information, access.

Split into breakout rooms for 60 minutes.

**Highlights from afternoon breakouts:**

|  |  |  |
| --- | --- | --- |
| Breakout Room | Facilitator | Breakout Headlines |
| **Adults with LD and/or Autism** | Paula Yassine | * Empowerment – assistance with mobility/ specialist support for access – TFL funding scheme * Accessibility – easy read information/ accessible self-referral portals |
| **Children and Families** | David Kingsley | * Accessibility of opportunities – make sure youth services are accessible to all/ increase capacity of youth services * Coproduction – importance of services by you, for you – importance of engagement |
| **Younger Adults** | Chyna-Mae Whyte | * Importance of being kept socially connected/ safe spaces – have voice heard and involve families more * Ensure Activities opened to those with LD |
| **Older Adults** | Tony Wong | * Empowerment – improve understanding of Care Act and human rights * Better Monitoring of those living alone * Greater Transparency of thresholds and what can be offered – Can VCS fill in gaps * Reintegration of elderly – focus on smaller groups * Accessible info – larger font sizes / digital exclusion * More joined up working across health system and VCS * Consideration about how groups are run when services change to in person, still lots of anxiety around COVID-19 |
| **Refugees and Migrants** | Caroline Hickey | * Capacity and investment - Need for greater investment, not just funding but capacity investment into how the VCS can engage with the system * System optimisation - More frank discussions about how the VCS can work with the system and vice versa; the opportunities the VCS must teach systems about our unique and nuanced expertise, so we can work together more effectively * Advocacy - Those with lived experience may have different needs, the VCS can advocate upwards * Language – not just spoken word also mannerisms and consideration for people who English isn’t their first language * Health days – re-instating health days where primary care nurses would go to community centres and carry out vital sign measurements e.g. blood pressure, height and weight and give primary care advice to bridge access gap |

**VM** summed up some of the key themes of the day:

* Fear and feelings of abandonment – need safe spaces
* The value of agency, being able to self-advocate, ability to describe what you need
* Travel and transport accessibility
* Information distribution; knowledge is power. Truly accessible information and language
* Statutory services could be commissioned differently in order to make people feel more included and improve people experiences of receiving a service
* How the VCS can support statutory provision by providing holistic wrap around care; supporting people on waiting lists; helping people make sense of their experiences and the support they are experiencing

**VM** and **RJ** thanked those who attended. The Assembly was closed by the song ‘This Is Me’ by Keala Settle and the Greatest Showman Ensemble.

“…But I won't let them break me down to dust  
I know that there's a place for us  
For we are glorious

I am brave, I am bruised  
I am who I'm meant to be, this is me  
Look out 'cause here I come  
And I'm marching on to the beat I drum  
I'm not scared to be seen  
I make no apologies, this is me …”

If you have any comments, questions or thoughts, please contact [Assembly@hcvs.org.uk](mailto:Assembly@hcvs.org.uk)

If you would like to join the Supporting What Matters Assembly working group, or contribute to the Racial Equality Working group, please contact [Jessica@hcvs.org.uk](mailto:Jessica@hcvs.org.uk) and [May@Hcvs.org.uk](mailto:May@Hcvs.org.uk)

Appendix 1: Poem by Sarah Weiss

**SUPPORTING WHAT MATTERS – DISABILITY AND LONG-TERM CONDITIONS**

Living with pain, every day of one’s life,

Sometimes mild, others like a cutting knife.

Grinning and bearing it, resigned to one’s fate,

Often reliant on favours from a mate.

Struggling to keep up with daily chores,

Weather contributing to feeling worse.

Regular painkillers saved for the acute,

Chronic symptoms challenging, noisy or mute.

Coping with these stresses, day in and day out,

Not always easy to get out and about.

Considering routes and negotiating terrain,

Using the buses, sometimes the train.

Let’s not kid ourselves, it can affect the mood,

Could be aggravated by certain food.

Self-discipline, diet, lifestyle changes,

Difficult to sustain without incentives.

Support groups have their time and place,

Alleviating isolation, which is a menace,

Not feeling alone, can halve the pain,

With like-minded individuals, so much to gain.

Diverse and faith communities, not always catered for,

Lacking cultural sensitivities, forgotten and sore.

Expert patient programmes, education and more,

Beyond their reach, but oh so helpful for sure!

For those incapacitated needing health and social care,

Using community providers who are so very aware,

Of culture and traditions and the calendar they share,

Tailoring visits and assistance with compassion so fair.

Demands on stretched services growing day by day,

Covid 19 impacts, have their part to play.

Families struggling, to cope with their caring needs,

Of older disabled children, for personal care and feeds.

Emotional stability is beginning to wear thin,

When the accumulating struggles, makes it hard to wear a grin.

The reality of reduced income and Long Covid is so stark

And keeping up with life’s demands, snuffs out the spark.

Carers’ health beginning to fail as time wears on,

Advancing age of carer and cared for, not much fun.

Soldiering on, respite not really within reach,

Cultural Awareness, something to teach.

Many programmes and messages, ethnic communities miss,

As corporate, mainstream agencies can be remiss,

In accessing the hard to reach, not just about digital divide!

But community intelligence and understanding, a factor to decide.

Trusted community groups and individuals can achieve so much!

A bit of extra funding can be made to stretch.

Whether to service volunteers, support groups or training,

Or share information through language use or mailing.

A deceased, isolated person could have been saved

If there had only been regular contact, hello, or a wave,

Push aside the paperwork, which is so disproportionate,

To allow volunteers to visit and be compassionate.

Universal is not uniform to improve inequality,

When we are dealing with the ethnic and faith community.

Insight and intelligence we must value and appreciate

And use community assets, before it is too late.

Appendix 2: Assembly Newsletter December 2021

**Assembly Newsletter December 2021**

**Aim of Assembly process:**

* + Shift power and resources to frontline VCS organisations
  + Placing communities in the lead for development of solutions

After each Assembly, we build on the problem solving with the community and partners to develop proposals by:

* + Interviews, discussions and working groups, ensuring community co-design throughout
  + Continued collaboration with statutory partners to achieve shared outcomes to reduce health inequalities
  + Adopting a test and learn process

Output and outcomes: New or redefined partnerships; programmes and projects that deliver new services/pathways that improve health and wellbeing outcomes.

**Assembly 1: Emotional Wellbeing**

**June 2021**

**Attendees: 189 individuals, 54 VCS organisations**

**Key outcomes (commissioning suggestions from VCS):**

|  |  |
| --- | --- |
| **Children and Families** | * A primary school to secondary school transitions service * Children and family support for children or adults in crisis/preventing crisis (step down from tier 4 to tier 3) or step down between secondary and primary care. |
| **Youth Services** | Increased clinical supervision to support staff and volunteers |
| **Refugee and Migrants** | Funding for individual organisations to provide increased support to refugees and migrants |
| **Disabilities and Long-Term Conditions** | Increase holistic support; increased provision for group and 1:1 activities |
| **Adult mental health** | Funding for the befriending support service capacity to recruit to more volunteers, increased support for carers |
| **LGBTQi+** | Increase in gender and sexual diversity training for Muslim support groups; increase local support for trans’ groups; funding to middle Eastern support groups |
| **Systems and commissioning navigation role** | There are several different services across CH but support is required to help services to navigate one another; input to understand and support commissioning requirements. |

**Key Progress:**

* Developed solutions through assembly, interviews and focus groups
* Business case developed with 8 proposals, progressing through discussions with NHS partners:
  + Mental Health Commissioner, City and Hackney CCG;
  + Director of Integrated Care, East London Foundation Trust;
  + Neighbourhoods Director, City & Hackney CCG, East London NHS Foundation Trust
* Applying anti-racist commissioning principles to commissioning
  + Including – transparency, ability to apply in consortiums, opportunities well publicised
  + Assembly insights provided an evidence base for securing Public Health England Mental Health grant funding, with a new grants programme to be launched soon, in partnership between LBH, Hackney CVS, and Mind
* London Borough of Hackney's Public Health Team has won £500'000 of funding to improve mental health support for communities presently under-represented in statutory mental health services. This will be made available to the VCS through a grant process to be run by Hackney CVS with funded projects being overseen by MIND. The money was won with a body of evidence highlighting underrepresented communities drawn from Assembly 1
* Applying anti-racist commissioning principles to commissioning
  + Including – transparency, ability to apply in consortiums, opportunities well publicised
  + Assembly insights provided an evidence base for securing Public Health England Mental Health grant funding, with a new grants programme to be launched soon, in partnership between LBH, Hackney CVS, and Mind

**Assembly 2: How can we make City & Hackney anti-racist?**

**October 2021**

**Attendees: 160 individuals representing 70 organisations (10 Statutory, 60 VCS orgs)**

**Proposals currently in development:**

* **Reducing Exclusions** – maximise VCS opportunity to reduce exclusions in local primary and secondary schools, and work towards positive school experience for all, consortium developed with 8 community groups, working with Director of Education in Hackney Council
* **Safe space development** – opportunities for young females affected by bereavement or gang violence to come together e.g., through talking groups and football
* **Training** – creating culturally appropriate directory of VCS training available
* **Positive representation** – opportunity for upcoming creatives to develop networks and events focused on positive representation

**Key Progress:**

* Working groups self-nominated from previous assembly, made up of:
  + Place 2 be, Peer, Community African School, Hackney Council, MRS Independent Living, Shelter, Outward Housing Support, ELFT, Youth Leaders at HCVS.
  + With more groups developing individual proposals
* An insight report from Assembly two was written with a view to tapping into a possible system-level communications funding pot

**Be part of Assembly 3 – Supporting What Matters working group**

* + Backfill available for time spent
* Join ongoing co-design work from Racial Equality Assembly
  + Add your training offer to the directory of culturally appropriate VCS trainings available – contact [jessica@hcvs.org.uk](mailto:jessica@hcvs.org.uk)
  + Get in touch if you have something to say in proposal development for positive representation, safe spaces & reducing exclusions
* Look out for future mental health grant funding through HackneyGiving and managed by Mind to be available – timings TBC
* Read HCVS newsletter for updates