

Health Inequalities:
What have we heard?
January 2021

From December 2020 to January 2021, we spoke to a number of organisations to find out their ideas for what services can do to improve their offer for the people they work with. The organisations were:

- LASSN (refugees and asylum seekers)
- Health Access for Refugees Programme - Refugee Council
- Solace (refugees and asylum seekers)
- The Migration Team at Leeds City Council
- Chapeltown Citizens Advice (people with mental health conditions)
- Autism Aim (autistic people)
- Carers Leeds (unpaid carers)
- Epilepsy Action (people with neurological conditions)
- Leeds CIL (people with impaired mobility)
- Memory Lane Day Centre (people with dementia)
- Home-Start (single parents)
- People in Action (people with learning disabilities)
- Leeds Older People's Forum (older people)
- Volition (people with mental health condition)
- Men's Health Unlocked at Forum Central (men)

We asked them:

1. What could health and care services do better or differently for your community?
2. What might work even better?
3. Have you seen any examples of good practice?
4. What would amazing look like?

We have an interview booked in with Leeds GATE and would also like to develop the work around the culturally diverse communities. In addition there is learning to add from the Inclusion for all action hub (which has been focusing on adherence to Accessible information standard), the Digital Inclusion work and the How does it feel for me? Work which have all identified key asks of health and care services.

Refugees and Asylum Seekers (part 1)

LASSN

What could health and care services do better or differently for your community?

1. Make a clear unambiguous statement of when and how interpreting services will be offered at each point of contact, and an explicit minimum standard of help - along with how to complain if this is not offered (GP, LCC helpline)
2. Better access to bilingual advocacy services, in acknowledgement that asylum seekers and refugees have some of the worst health in the city
3. Stop implementing the NHS Overseas Charging regime for people with no right to work, no right to a bank account, and no income - and tell central government NHS Improvements that this is negatively impacting on the health strategy for Leeds as well as being morally wrong, especially when it comes to survivors of abuse and mistreatment.
4. A 3-point plan, adopted by Health and Wellbeing Board and championed by a senior member of the HWB Board, to address the systemic problems encountered by migrants living in Leeds (including refugees and asylum seekers), and progress against these reported every quarter. Nothing fancy. Nothing too hard. But a steady way of improving the lives of the 10% of people who were born outside the UK and living in Leeds.

Refugees & Asylum Seekers (part 2)

Solace

What could health and care services do better or differently for your community?

Services need interpreters and multi-lingual literature because a lot of Solace's client groups don't speak English.

Services should also use a destigmatising approach towards mental health problems, using positive language more about emotional wellbeing as opposed to mental health problems.

What might work even better?

A lot of clients find it hard to make contact with GP surgeries so outreach work and finding people who might be in need.

Any examples of good practice?

Solace has found it helpful to identify a specific need and gear a service directly to that (for example, a wellbeing group for Albanian women). It's about understanding the cultural sensitivities of what the needs of a group might be.

What would amazing look like?

Train members of staff to have sensitivity of what clients are going through and what they have been through. Staff should understand that they often don't have one problem but many problems (including a lot of physical health problems).

Refugees & Asylum Seekers (part 3)

Health Access for Refugees Programme - Refugee Council

What could health and care services do better or differently for your community?

It is common that GPs charge for letters. Not everyone can afford to pay.

There are issues with interpreters not being used. Some practices will not give people an appointment unless they bring their own interpreter, which they must pay for themselves. People without an interpreter often get turned away. GPs, dentists and health/care services should be providing interpreters.

GPs should follow government policy by not asking for ID when trying to register. People will not be able to get a COVID vaccine if they are not registered, as they need an NHS number.

Accessing dentists has been impossible, particularly for asylum seekers.

People should be informed that they can book a double appointment if they do not speak English.

People should be told who does what in a GP surgery. (For example, when people see a nurse instead of a doctor, the fact you need to get to an appointment on time or what time is best to call for an appointment). In other countries, people go to the hospital to access health care, but we don't want A&E to be overcrowded. Not everyone knows the UK process of referrals to a specialist.

It would be nice to see a welcome sign in practices.

Surgeries need to get Doctors of the World training and become what is known as a "safe sanctuary" so they understand the barriers that people might face. HARP give free training to health professionals on this.

What might work even better?

Working on building a trusting relationship: doctors need to turn away from their computer screens and talk to the person in front of them, use interpreters, smile and understand what they are going through.

Any examples of good practice?

Haamla midwives are excellent. They are for women seeking asylum, new refugee arrivals and Gypsy community and. When people access healthcare, they should have an automatic referral to this service. The

midwives reach out, visit and write letters for people. Bevan is another good practice. They are kind and welcoming.

Migrants

Migration Team, Leeds City Council

What could health and care services do better or differently for your community?

Digital access:

- When designing services, be aware that migrants' phone credit is often limited and third-party organisations often have to step in to give people private space for contacting services digitally

GP services:

- GPs and receptionists should be fully trained in migrants' and visitors' entitlement to access NHS care
- People aren't being made aware that they can book a longer appointment if they don't speak English as a first language
- There should be greater understanding of the entitlements of people who don't have access to public funds.
- GPs should be aware of their powers to speak to women without their husband present where domestic violence is suspected
- Staff should have some cultural awareness of how people might express their pain in trauma in different ways. It's more than translation issue, it's about understanding how people communicate more broadly and how difficult it be to talk about trauma with staff who may not be able to relate with their life experiences
- Burmantofts health centre requires refurbishment to make it a bigger, more welcoming surgery.
- Place people on hold when calling through rather than having a busy tone and having to call again
- Use videos in GP surgeries (in the foyer) to share information messages in different languages (lots of people sit there and have nothing to do but watch when in GP surgeries).

Families and children:

- Health visitors don't always signpost women to services that can help them, so they are left unsupported

- The impact of lockdown on children's mental health will be an issue for a long time to come - we need to prepare for this now.

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Autism

Autism AIM

What could services do better?

Improve access to GPs

People with autism have a high rate of co-occurring conditions and differing communication and sensory needs which means that accessing a GP can be more difficult. Here are some of the reasons:

Getting to the GP

- If they are isolated, they might not have someone to go with them (no support network itself can be a barrier), might not be eligible for or be able to afford a support worker.
- Having the same doctor so that people don't have to explain themselves each time and, once a GP gets to know the patient, they will form a better relationship and understanding of the person. Could priority access to the same GP be given to people with Autism?

At the GP

- This is where having someone with them would really help, as often retaining the information given by a practitioner is difficult, which means they might not understand what to do next. Could it be standard practice for GPs to put something in writing so that people with autism can take it away - e.g. information discussed and follow up appointment details?
- Not all people with autism are flagged or are asked about autism when talking about reasonable adjustments - so autistic people might not know whether to tell someone about it or how to raise it. Could this be standard practice when asking about reasonable adjustments?
- As processing time could be slower for Autistic people, could their appointment times be extended as a matter of practice instead of leaving it up to the patient to book extended sessions?
- Receptionists are a real mixed bag - some have no autism awareness at all.
- Waiting room: a quiet waiting room would be preferable for autistic people due to sensory sensitivities. Something as simple as receptionists' phones being turned down could be beneficial. Could there also be some specialist Autism practices in Leeds? There are practices that specialise in other areas.

- Doctors understanding of Autism varies widely (with some people experiencing doctors that “don’t believe” in Autism). So Autism awareness training and understanding of how some people respond to questions would be beneficial. A good example of this is when being asked about pain levels. Sometimes people are asked on a scale of 1-10 or judged by their body language and facial expressions. Some autistic people could be in severe pain and not show it or could verbalise using words that make sense to them but not necessarily the doctor. This can lead to the doctor dismissing or not judging the level of pain the person is in. A person could also get sensory overload and again be dismissed as being hysterical or panicking.

Other things to consider:

- Whilst E Consult can be useful as people won’t need to speak to the receptionist, there is a downside. A lot of the questions asked don’t always make sense, e.g. it might ask what the problem is and the next question ask what the symptoms are or ask about medication twice. It can get very confusing and a lot of people with autism would give up. It would help if there was some guidance on each question, e.g. an explanation on why you are asking this particular question.
- GPs in York have a badge/award to say that they are Autism friendly. Advonet are doing some work with the diagnostic service to get something similar in Leeds.
- There is a higher occurrence of LGBT+ in people with autism, in particular trans and identifying as non-binary. The language used to express themselves and communication issues that people with autism have can make accessing things like gender clinics especially difficult.

Single Parents

Home-Start

What could health and care services do better or differently for your community?

A more flexible, understanding approach:

- Services should offer parents appropriate appointment times, taking into account their childcare needs and offering support where possible
- People's personal circumstances can represent barriers to attending. When people don't attend their appointments, they shouldn't be "written off". Workforce development offers a way to do this, so that staff will be trained to think about what is going on in people's lives.
- Having an offer that includes different approaches can help to include people.

Joint, community-based working:

- While there have been moves to make services more local, but barriers still remain.
- For example, there have been initiatives in recent years to find out if third-sector organisations have rooms they could open to services, the idea being that these would be more welcoming and familiar to some people. However, these haven't come to fruition because organisations can't afford to upgrade their facilities; they also can't be confident that investment from services would be long term.
- Third-sector organisers can be part of a more comprehensive system that takes a holistic approach to individuals' circumstances (which might include, for example, domestic violence, mental health, special educational needs and disability). However, it should be borne in mind that smaller support groups seem to have disappeared in recent times, and capacity is a problem for many organisations.

Getting the language right:

- Services should be more mindful of their use of terminology (for example, ideally they would use "adult", "child", "young person" instead of "patient").
- Language should also be shared across services

- The third-sector has a lot to offer in terms of building trust with people

Prevention:

- Services are starting to think more and more about children and families (including Local Care Partnerships), but there is more room for preventative work. For example, prevention around perinatal mental health could help prevent problems from taking root early in life.
- Mental health is a huge issue at the moment, the consequences of which won't become fully clear for several years.

Coproduction:

- Ask people's views about services before putting things in place. There is still a tendency to ask people too late, when a project's parameters are already very much in place. Third-sector organisations can be a good conduit for this. If we get this right, we can support people the way they want to be supported.

What might work even better?

Collaborative partnership work:

- The connections Home-Start has made at the Communities of Interest network have been really useful
- As things start to get tougher in the sector over the coming months, there is a worry that people will start to retreat back into their own organisations (although it's been clear that collaboration makes us all stronger!)
- It's important too that small organisations (such as Home-Start) don't get forgotten. Those which are reliant on grants have to worry all the time about sustainability, making it much harder to plan long-term. You can't build any foundations if your funding is at risk year-on-year, and it also makes organisations more reluctant to offer long-term engagement to people, as they don't want to have to disappoint them when the funding goes.

Flexible service offers

- Especially at times of lockdown, flexibility is an important part of any service. While services are starting to offer out-of-hours appointments, this could be rolled out more widely.

- Being able to access services remotely has been fantastic for those individuals who can access them. It would be great to see a blended offer being available over the long term.

Any examples of good practice?

- Home-Start has a great relationship with Early Help Teams, Children's Centres, Leeds Mental Wellbeing Service, which enables them to offer "wraparound" support for families. This works because it reflects the fact that "one size doesn't fit all" (i.e.: some people are more likely to engage with one service than another).
- Home-Start Leeds is part of the Leeds Mental Well-being Service (LMWS). While the service at the Mount isn't perfect yet, the partnership has developed and the whole service and pathways are still being looked at. It is important that small voluntary organisations are not forgotten.
- While there is still progress to be made around culture and language, it's good that honest conversations about them are happening.

What would amazing look like?

- Whoever the service user is, whatever their age, they get the right support from the right team.
- Services are restorative and are based on the person's strengths, rather than what they can't do (for instance, there is recognition that we all react to life events in different ways, so we have to accept this into our expectations about how people should behave).

People with Learning Disabilities

People in Action

What could health and care services do better or differently for your community?

Mental health

Appropriate mental health services for people with a learning disability are really difficult to find. Some people access IAPT but it's limited to a certain number of sessions - this increases anxiety before even getting access as there is a fear of missing an appointment and being 'dropped' from the service.

Lots of people with a LD also have a mental health diagnosis and tend to fall between services. They often end up with LD support organisations such as People in Action which don't have the mental health expertise to fully support them. People in Action has seen an increase in people experiencing mental health crisis, particularly men who are isolated because of COVID.

People in Action try and support with social prescribing and regular check-ins but isn't mental health trained.

Domestic abuse/violence

There are some good links but no tailored support or understanding of what people with a LD need or the barriers that they face.

Medication reviews

Some people have been on the same medication for years and, in a lot of cases, medication reviews are not happening with the GP or the GP is not reviewing the medication during appointments.

Sometimes there is a change in the person's behaviour and it can take a lot of phone calls to get the GP to review. One example was a member of People in Action who has had a lot of falls, but they were met with reluctance when trying to get a review. Staff working with people with LD are not medically trained so, if the GP says there is no need to review, should staff accept it and not push? People in Action are looking at some training around medical conditions for people with a LD.

Annual Health Checks

Everyone with a LD should be called for an Annual Health Check, but some people are not being called for them. There is also an issue with

some parents saying that their child (with a LD) doesn't need the annual check-up. There are potential preventable deaths because of annual check-ups not being done.

Where people are in supported living or residential settings then support organisations tend to know more about medical records and the person's health. If the person is living in a family home, the support organisation often has more issues. Families can be quite protective so there are more barriers in working with family carers on medication reviews and mental health issues, especially around changing appointments.

If health services could work with support organisations and family carers that would help joining things up more and organisations like People in Action could work more closely with the family to help allay any potential fears.

Sexual health and gender identity

Quite often there are barriers with parents not wanting to accept their child. If support organisations could be more involved (for example by being signed up to Leeds Care Record) it would really help. Currently, organisations spend lots of time trying to support people and calling lots of different organisations for information.

Accessible Information

Easy Read is helpful but always seems to be an afterthought. While there has been improvement (especially in relation to COVID), Easy Read isn't a "one size fits all" solution. Finding out people's accessible information needs is key.

What would amazing look like?

More joined up services: attending the Local Care Partnership (LCP) has made a real difference for People in Action in getting information quickly and being involved in discussions early relating to LD. For example, at the York Road LCP some work was being done around employment training that wasn't accessible, but People in Action are now involved to make sure this changes.

Thinking about how services work for people with LD (especially in the planning stages) would make a lot more things amazing. Use the skills, knowledge and experience of staff (at organisations such as People in Action) to help plan new or changing services.

Carers Leeds

Ensure carers can take breaksmore respite opportunities, planned weeks, home based care with a more holistic view of caring for whole person (not task orientated) and the family carer.

Priority on carers' health and wellbeing.

The return of essential services must be prioritised (in a safe and managed way)

Ensure carers can continue to remain in work (if they wish). Continue our work with our Working Carers Business forum as well as the Leeds Anchors Healthy Work

Ratchet up carer ID and support across all health services (GP, hospitals, community). Its happening but much more to do.

Prioritise vaccination for unpaid carers

Develop a carers card

(Nationally: increase Carers Allowance to at least the same as Jobseekers Allowance)

Ensure good digital access but also paper info too. Find out HOW carers want to be communicated with

A one off payment to help carers through the winter months and as recognition for what they've done over the last 9 months keeping the cared for person safe and well and ultimately way from mainstream services

Continued support for bereaved carers (Covid related)

All of the above AND

Carers support across Leeds based in communities. Not only city centre.

Choice of support in person or digital

Making sure every carer has the digital kit to access our services (and other support)

Take support out to people (bus in car parks of supermarkets and community centres)

Carers UK Caring Behind Closed Doors

<https://www.carersuk.org/news-and-campaigns/campaigns/caring-behind-closed-doors>

Men

Men's Health Unlocked

What could health and care services do better or differently for your community?

They should recognise that making an appointment is very tricky and that men can struggle more with communication.

They should also have an understanding of men's lives. A lot of policies are put in place without an understanding of what it is like to be in poverty. For example, advising that one should try meet others more is of no use if that is not facilitated at the same time - it will just create a barrier and make "healthy" an inaccessible notion when in reality there may be other ways in which one can be healthier.

Any examples of good practice?

Examples include peer-led groups where men help to lead, for example Men in Sheds, Andy's Man Club, BEA Saturday Men's Group and the Zest Impact Group. Also, the Manbassador Project uses apparently unhealthy settings (such as a chip shop) to promote good health, because the proprietors provide high quality peer support to their customers.

What would amazing look like?

Consider men in policy.

Reinstate male-only services and offer healthcare designed with men in mind, for example by reinstating prostate cancer screening. In Leeds CCG, the last mention one can find of anything at all related specifically to men is something to do with Movember in 2017/2018.

Create domestic abuse support services that are more cross-gender, or target men specifically, given that around a third of victims are male and that they are less likely to report.

Older People

Leeds Older People's Forum

What could health and care services do better or differently for your community?

Where possible, health and care services could be mindful, adapt and respond accordingly to the ongoing and emerging issues reported by older people and organisations supporting older people. These include:

- The third sector is reporting a marked rise in referrals around mental health - including reports of mental health issues in people who have not previously been reported with mental ill health. There are increased levels of anxiety and panic attacks. Reasons reported include:
 - the winter season and trauma from previous lockdowns;
 - low self-esteem due to a combination of factors, including growing impact of isolation, lack of face-to-face contact;
 - the impact of being seen as one of the 'vulnerable' groups during the pandemic
- Increased fear amongst older people due to the impact of death reports from COVID-19, particularly at the 100,000 point and for those older people living in care homes; cancellation of a second vaccination date has brought further anxiety for some older people
- Older people with sensory impairments are experiencing extremely high levels of isolation
- Lack of face-to-face contact is also leading to deterioration in physical health, leading to deconditioning going unnoticed
- Older people who live alone and older men have been identified as particularly affected by isolation; older men are more reluctant to engage in support services and online groups
- Digital exclusion is an issue, especially as online services become more prevalent and prioritised
- Increase in concern regarding domestic violence and substance misuse has been reported by Age UK Leeds

- Lockdown and isolation have magnified grieving for past and present bereavements

Any examples of good practice?

Deliveries by the third sector are successfully being used as wellbeing checks.

Keeping in touch calls, welfare calls and befriending have all been extremely valuable contact.

Many organisations have adapted to offer resources and support with digital inclusion, often with support from 100% Digital.

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Mental Health (part 1)

Volition

What could health and care services do better or differently for your community?

- Keep having an online offer as well as a face to face offer, and being able to change between the two depending on what's most convenient.
- Put co-production at the heart of service improvement - make sure it sets the agenda, rather than responding to an agenda that is already fixed. Make sure broad segments of the population are involved and represented, whilst acknowledging that people can't represent their entire community/demographic - it is far more complex and nuanced than that, there are no easy answers
- Organisations fostering a community - feeling more like a community than a service, moving away from medicalised models where appropriate.
- Trauma-informed practice embedded into all health and care services, to lift barriers to services for many of the hardest to reach people.
- Combine exercise and social connection in different contexts to typical exercise classes, for people who wouldn't ordinarily join - as physical activity and social connection are a mood-boosting combination in terms of early intervention/prevention work.
- Continue learning from the "I statements" (National Voices Network): people want to be treated compassionately, feel listened to and have agency. They want to be helped by an identified person with a name, and have access to culturally appropriate services that are relevant to them.
- Try to ensure people don't have to keep repeating their story to different staff members, as it can be retraumatising.
- More mental health support for people in care homes.
- Ensuring, when supporting people who can be harder to reach within medicalised mental health models (e.g. older people, men, some people of colour), that mental health language is more softened and relationship-focused, so it's more accessible for those who still strongly associate mental health with stigma or shame.

- Eating disorder clinics need to not tell their patients that they are 'not thin enough' to access treatment - it is life-threatening language and has huge power.
- Work to try to reduce stigma around sex workers accessing mental health services, as they are often met by judgement, or told that the sex work is the root of their issues and they should stop doing it to solve their mental health issues - this is a very exclusionary approach and we know it isn't working.
- Have more services that allow people to engage even though they are still using drugs and alcohol - balanced of course with the safety of the staff. It becomes a chicken and egg situation where people can't get off drugs and alcohol without that support, but they can't access it - new online models could be key to this work.
- More stepping up and stepping down of care - less of a cliff edge when you are discharged - using third sector peer/social groups and early intervention provision to keep people connected, and ensuring that this translates to more intensive support as and when people need it.
- Keep striving to improve communication between services to ensure a better service-user experience and pathways to and from support - continuing to strengthen links between mental health services and services that support the wider determinants of health.

Any examples of good practice?

- In Mafwa Theatre, a staff member from Leeds Mental Wellbeing Service (Nasia from Touchstone) comes into the group to be a familiar face and build relationships, so that they feel they can come to her for support if needed - this is such a brilliant model and they have said it's really working.
- Leeds Irish Health & Homes is a really strong example of building a community rather than a service - the result is high engagement and trust from their members, and a really accessible atmosphere.
- Armley Helping Hands have bought 4 ebikes and are planning to do cycling trips with small groups of members - rather than always taking a van, where they can, they want to trial these trips, so that members can exercise as well as go on a day out. Is a great way to minimise COVID risk whilst still being able to do day trips (post lockdown), and combined exercise with social connection.

- Victim Support have developed an online resource called My Support Space which they use in addition to support - it includes guides on topics like trauma, recovery diaries and the ability to 'request support' - very interesting model for low level support.
- Citizens Advice Leeds & Chapeltown are an incredible access point, both to crisis services and the wider determinants of health.
- Leeds BME Hub is an excellent example of coproduction - the members set the agenda and the facilitators are there to support them, not to lead them.

What would amazing look like?

- There are a lot of useful learning in a model like My Support Space when we think about the stepping up and stepping down of care and what that could look like. I would love to see people able to have an online hub for their care, full of guides to help with low level mental health issues, e.g. a toolbox of coping mechanisms to try, rate and embed using principles of habit formation, with an easy, really accessible way to self-refer if they need more intensive support, as they would already have an account with all their key details on it. Once this learning leads to a really effective model being produced, it will be the future of health and care. There are so many apps on NHS digital that could be embedded within this model and it would be a great way for clinicians to be able to build a holistic picture of the individual and what keeps them healthy.
- Calm Harm is a good example of a resource (app) with embedded toolkit of coping mechanisms.

Poverty and Mental health (part 2)

Chapelton Citizens Advice

What could health and care services do differently for their community?

1. Have a real understanding of the systemic racism that pervades the institution and act upon that.
2. Adopt a paradigm shift towards patient centred services that shift some resources away from the clinical power house.
3. Truly understand the link between poverty, social justice and health and wellbeing and act upon that understanding

Moneyandmentalhealth.org states that in any given year, one in four people will experience a mental health problem, and over a lifetime this rises to nearly half the population.

People with mental health problems are more likely to be living on low incomes or in insecure work, and can experience a range of difficulties accessing the benefits system. Common symptoms of mental health problems, like low motivation, unreliable memory, limited concentration and reduced planning and problem-solving abilities, can make managing money significantly harder. As a result, it is estimated that people with mental health problems pay up to £1,550 more per year for essential services than people without mental health problems.

Currently Chapelton Citizens Advice is very aware of the impact on mental health of COVID-19 and the necessity of living within lockdown and all that entails from its own client base. In August Cit A estimated nationally 6 million people have fallen into debt since the pandemic began - more so in the North of England. Nationally it is estimated that 350,00 face eviction because of rent arrears.

Inevitably this will impact further on the mental health of this City and given the link between poverty and COVID-19, Black communities and COVID-19 and Black communities and mental health we can easily identify which communities are going to be the hardest hit and where interventions are best placed to prevent poor mental health developing into a chronic condition requiring clinical interventions and resultant higher expenditure.

We also know that these same communities are going to be impacted more so by the recession and any following austerity measures and so their health and wellbeing is under ever increased threat. The city's long-standing aim of reducing health inequalities and inclusive growth will require a well-coordinated approach that needs to be built now.

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Neurological conditions

Epilepsy Action

What could health and care services do better or differently for your community?

Diagnostics

In order to get a diagnosis for some neuro conditions there are a lot of tests, so you are dependent on being able to access a number of areas of clinical pathways before getting to your diagnosis appointment. If one part falls down (e.g. have had one test but waiting months to get a result) then the time to get a diagnosis gets longer, meaning treatment can't start.

Getting a response

People have been without an appointment for a long time as they have not been able to contact their service. A lot of people with a neuro condition have a specialist nurse that might be based in hospital or community teams - people are used to having 6 monthly appointments and are given a phone number to ring if they had a relapse, but lots of people have not been getting a response on those numbers. They either get a voicemail saying there is no one to contact or being referred to GP but GP is not an expert in neuro conditions. People are waiting a long time but might not need to be physically seen if they were called back as it might just be a question of adjusting medication.

Patient Initiated Follow Up work is going on nationally - a patient might have been discharged but told if they have a flare-up they can get back in touch with specialist nurse, but if that is not happening then GPs have to do referrals and that gets more complicated.

Rehab services

People that would have normally been doing important exercises, etc., have not been having hands on support and their conditions have deteriorated. If you've had a stroke or a disease of decline, then rehab is so important.

There were beds for neuro rehab and day centres but it is now difficult to get patients transferred after acute treatment to recovery - probably as much a workforce issue as anything. Are long COVID teams being set up, leading to areas of rehab are being de-prioritised?

What might work even better?

A more person-centred approach

Some people have been scared of going into hospital, so more things being done at home is potentially good. However, while some virtual appointments have been good, others have not - e.g. a phone appointment where an exercise is explained is not as good as having this done via video.

There are model systems in other countries where practitioners come to your home with the relevant equipment, e.g. a skull cap where EEG are sent to hospital to help with diagnosis. In Leeds you need to sit in a bed in a unit where someone would be watching you for a week so they can spot if you have seizure activity. If a camera could be set up at home that would be better than a week in hospital.

What would amazing look like?

Joined up records between services - a lot of people with multiple long-term conditions are seen by a lot of different services and are on multiple medications. They have to re-tell their story everywhere they go.

However, if the person has had a stroke, for example, they might not be able to tell them about their condition, so shared records are important. It might mean that some people don't need to be taken to hospital - might be more appropriate to call a specialist nurse. It's a difficult call for paramedics to make this decision if they don't have access to the records.

When long-term conditions are mentioned, there is often a focus on things like diabetes or heart conditions. If you have a neuro condition, you are not as often brought to the table.

Dementia

Memory Lane Day Centre

What could health and care services do better or differently for your community?

- There has been concern from carers of people with dementia around **support following a diagnosis**. People get a diagnosis of dementia and there is no support or regular check - how does anyone know how the condition is progressing? It seems to be left until the next annual review.
- If people's care is privately funded, they don't get a social worker so don't know where to turn. Sometimes support might be offered to the partner of the person diagnosed but not to the rest of the family who often offer the main bulk of care.
- There needs to be a regular assessment - people won't often reach out unless prompted or in crisis. The Admiral Nurses do a great job but, in Leeds, people have to have some affiliation with the armed forces to access them.
- There is not enough recognition about low mood/depression for people, both patient and carer, who have been diagnosed with dementia. This ties in a bit with the lack of support - there is no offer of counselling. Patients and carers need to be told that it's not all doom and gloom.
- There is often not much understanding about why people are taking certain medication so more clarity around that would be beneficial.

What might work even better?

- If there was a 'one stop shop' for dementia.
- More Memory Support workers would be great. It's not always clear how people get access to a Memory Nurse - some come from Primary Care and some from MH but it doesn't seem like it's always offered.
- Promote (and more funding for) Memory Cafes - they offer lots of respite, support and activities that are fun, bring people out of themselves and get people living again.
- There aren't enough Day Centres anymore (and they are not promoted - possibly because they are fully subscribed already).

What would amazing look like?

- Having a directory of dementia services and support available on diagnosis. This could include links to dementia awareness training. Often people don't fully understand dementia and how to deal with it. Having access to this information from the start would be helpful, especially to the family.

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