"Living Well in Manchester"
Engaging with disabled people on health issues within the One Team and place based care approach.

Final Project Report April 2017
This is the final report from this engagement work. It covers key points and themes raised by disabled people we spoke with, and makes recommendations for inclusive good practice and planning within the One Team approach, based on disabled people's lived experience of using health and social care provision in the city.

Project Outline
Manchester CCGs wish to understand the health needs of disabled people and their experience of accessing health services in Manchester in the context of the developing place based approach to health and social care.

Breakthrough UK was commissioned to do this. We conducted engagement events / conversations with disabled people across Manchester. Events began in late November 2016 and ran until early April 2017.

Breakthrough is a Manchester based disabled people's organisation. We are led by disabled people, and we support other disabled people to work and live independently.

Breakthrough works to make positive changes at an individual, regional and national level. We provide disabled people with person centred support to develop their independence and gain access to training and employment. We advise employers, policy makers and other organisations to understand and remove barriers that disadvantage disabled people. Our aim is to bring about a society where disabled people can participate fully in all areas of life.

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Methods

We engaged with disabled people by:
- Meeting with existing groups of disabled people across the city.
- Holding conversations at venues where disabled people are likely to frequent including community venues, leisure and support services.
- Discussions with Breakthrough UK clients.
- Virtual engagement.

We held group and individual discussions with **53** disabled people who live in Manchester at:
- Breakthrough's Coffee Morning at Abraham Moss
- Conversation events at Levenshulme Inspire
- Stroke Café Moston
- Stroke Café Gorton
- Breakthrough Client Peer Group held in Central Manchester
- Art Group Moston
- Drop-ins at Wythenshawe Forum
- A Drop-in at the Yes Centre
- A workshop at the Greater Manchester Coalition of Disabled People (GMCDP)
- Surveys (nine people in total)

Some groups also included family carers and support staff (not included in totals).

With support from a corporate donation, we were able to widen the remit at some of the longer conversations to gather additional evidence on disabled people's experiences of independent living and changes to support.

Many of the conversations operated by 'piggybacking' onto existing established group meetings already taking place, rather than stand alone meetings. The latter were not as well attended.

Conversation format:
1. Discussion and information giving on the One Team approach and 'placed based model' of care in Manchester. Focus on neighbourhood teams and potential benefits for individuals.
2. How do you want to be treated by health & social care providers? Including good practice examples where possible.
3. What makes it easier for you to access health & social care? What sorts of things enable you to be fully included in your care or support?
4. What are the gaps? What can't you find? What needs to change? How?

What do you need to live well and stay well?

At the longer conversations there were also discussions on a) barriers to / enablers for independent living and b) about people's experiences of community connection - and how they would like to contribute.

At many of the earlier conversations, we spoke with disabled people who were not linked in with disabled people's organisations like Breakthrough - a number of whom had recently acquired impairments and were exploring what was available to them. By contrast, at two of the later conversations (the second one at Levenshulme Inspire and the one at the GMCDP) we spoke with people who are generally more informed about their rights, are politically active in the disabled people's movement and have been navigating the health and social care systems for some years. Overall the feedback across the conversations was quite consistent. Where there were significant differences between the responses of groups, this is highlighted.

Summary of key themes emerging from the engagement work:

- Feedback on the One Team approach was largely positive, although some participants were very sceptical that all is achievable in an austerity climate.
- Access permitting, people were very keen on a 'one stop shop' hub approach to neighbourhood provision, covering wider features such as information provision.
- It was striking how few disabled people we spoke with had heard of the One Team approach (or aspects of it), had knowledge of any changes to health and social care in Manchester and how it affects them, or of the wider messaging around devolution such as those around people taking charge of their own health. It is clear that these messages are not getting through to many disabled people via conventional engagement routes and a different approach is recommended.
- People want to be listened to by providers, be fully involved with their support / healthcare and have opportunities to shape its development.
- A lot of disabled people we spoke with were disadvantaged in social capital and agency, experiencing both economic and social exclusion.
- Structural barriers to accessing provision – including those of information, bureaucracy, attitudes and to the physical environment - were highlighted at every conversation.
- Participants therefore called for training for providers in the new structure – specifically around the social model of disability, attitudes and communication.
- Many of these points would be also be addressed through more enforcement of providers' anticipatory duty to make reasonable

adjustments under the Equality Act, and through a more thorough adoption of the Accessible Information Standard.

- People spoke about cuts, and about how these are impacting on their access to, and experience of, health and social care services provision.
- The All Age Disability Strategy is now being implemented in Manchester, and this is an ideal opportunity for all providers to level up to good practice across all of the 12 Pillars of Independent Living across its respective sub-groups.
- It is clear from feedback that disabled people's experiences of health and social care provision is very affected by the availability of other elements of independent living. Accessible transport, accessible information, advocacy, physical access and the availability of peer support were especially important to the people we spoke with.

Findings

Reaction to One Team model
Very few people throughout the project had heard about the One Team approach (only six people altogether) and fewer of these knew what this meant in practice. A small number of people had heard about devolution more generally.

Participants at workshops and conversations said that it was very helpful to find out about what was changing in Manchester, and about how it might affect them. There is more work to do to raise awareness of the One Team approach amongst disabled people. The publically available information on https://healthiermanchester.org/ needs to be cascaded to groups across the city, and made available in different formats.

The majority of participants felt, in principle, that the One Team approach was good, especially around having a single key worker and not needing to repeat information: "I have to tell people the same thing a dozen times".

Mostly, disabled people agreed that a named point of contact would be an advantage. One person said that they are afraid of losing the contact they have with the same person "Things are always changing". Another said: "Familiarity seems to be the key – for example seeing people in person and knowing them". Disabled clients of Breakthrough wanted to "see the same person every time" when working with healthcare providers and get one to one support from them, not in a group. 100% of survey respondents want to see the same person each time.

People were curious about who their key worker would actually be. One participant, who lives in an environment with a flexible key worker system, said this approach works well there because there is choice about who their key worker is (would that be the case here?).

There was some scepticism about how information sharing across teams would work, would the Single Care Record involve costly IT systems for example? But people largely agreed that it needs to be more joined up: "central records which link to all the relevant people you see".

A couple of people also talked about having access to their notes: "as often professionals don't have time to read/get up to speed with everything – so I have to keep my own records."

Participants also mostly agreed there was too much duplication and many were very keen on the idea of having co-located neighbourhood teams, as long as getting there was accessible (see section on travel).

One disabled person talked about a hub local to them which has various practitioners on the same site including doctors, dentists and physiotherapists. They said they found this more streamlined, quieter and less anxiety provoking to use: "It's a move forward".

Another person talked about the Gateways in Salford which are hubs where libraries take the lead. They said that an advantage of this approach is that the library staff are very knowledgeable so can support people with good information about what's available.

Two people at the GMCDP workshop felt very strongly that moves they had heard about to co-locate the Department for Work and Pensions (DWP) within neighbourhood hubs should not happen. "The DWP are a hostile entity to disabled people".

In two conversations, a concern was expressed that the merging of health and social care will result in too much of a rigid health focus - and some felt this is already happening. All providers therefore need to be aware of the Social Model of Disability and the need to work with people holistically. There is scope of this already embedded within the Wellbeing Principles within the Care Act, which are broad in focus.

The issue of cuts was raised by participants at most conversations. For example: "This is all against a backdrop of cuts", and "The wider context of all this is that effective social care support is not in place for a lot of disabled people already because of cuts." Some people were sceptical about the

effectiveness of changes for this reason.

At the second session at Levenshulme Inspire, we also had a brief discussion about the **prevention agenda** (e.g. Taking Charge Together). Participants felt that not all disabled people have control and agency over decisions around, for example, healthy eating and exercise. In terms of healthcare and lifestyle people need to:

1. Know they have a choice
2. Have the tools to make a choice
3. Not have assumptions made about their social agency.

The intersections between lifestyle and health management can be complex. An example given was of people using non-prescribed medication for pain control because medical options have not worked.

People need motivation to make choices and are not always able to act on them independently. Sometimes there is "too much stick and not enough carrot". Some people will need more support than others to do this, and this support is currently difficult for all who need it to to find, although we are aware that steps are being taken to address this gap in the city now via neighbourhood health workers and social prescribing.

Direct payments are another big issue when it comes to some disabled people's ability to take exercise. Some people have used Direct Payments historically to pay for support to facilitate exercise, but then their support hours were cut and they are no longer able to do this.

A related issue raised is the perception by providers that it's always going to cost more for disabled people to participate in things, or that there will be some risk attached. Many reasonable adjustments made by service providers cost little or nothing to make. The provision of reasonable adjustments to enable disabled people to take part in activities should not be based on perceptions of cost.

The role of carers in the One Team Approach
Most groups did not pass comment on the role of carers in the One Team approach. However, here was a lengthy discussion on the role of carers at one of the conversations.

Firstly, people felt that the 'benefits for people' information made an assumption that everyone has a carer.

Power and control exerted from carers was the main concern raised: "There can be dangerous power situations and more subtle ones between disabled people and family members which are hard to pick up."

Participants wanted to know how individuals could refuse the involvement of family members? Care Act Advocacy is very limited in scope and most disabled people would not be eligible for it.

It was also highlighted in this session that 'carer' and 'cared for' are not exclusive categories. Many disabled people have caring responsibilities themselves.

People in this group felt that issues around carers should be dealt with entirely separately. If disabled people need support from the One Team the there must be something in place to ensure that the 'carer' is not involved, either in the process or in information sharing. "It's down to the assessor to make the safe space."

Single Trusted Assessment
A particular concern at the GMCDP workshop was about the Single Trusted Assessment. The points in this section were all raised by participants at this workshop:

There were some very strong views: "The record on state assessments to date is very bad. I can't stress how bad it is. It's criminally negligent".

"If the assessment is wrong, where is the right to appeal? Second opinion. Where are the statutory resources? Where is the advocacy help? The legal help? Without this, it's abuse."

Participants here agreed that the assessment approach must be based on co-production and joint decision making: "Professionals having meetings without us there must not happen."

There was some discussion about what the single trusted assessment would comprise – people said it couldn't really be a 'single' assessment because it wouldn't cover assessments out of scope of health and social care such as welfare benefit assessments. People felt that the term needs to be qualified otherwise some disabled people may be misled and get anxious. There needs to be more clarity. Put health and social care in the name perhaps?

One participant said that they had heard that sanctions and workfare were going to merge into these assessments via the Work Programme in the longer term. This needs clarification as some people have been told this is

happening and are very concerned.

The point was also made that health and social care assessments are currently very segregated - so this is a positive move: "People with complex impairments fall down a chasm. Social care funding does not cover medical needs – they can't pay – but your Personal Assistant may be helping you with 'medical' needs, for example gastro feeds and transfers. You can only get social care paid for by the NHS if you are very profoundly impaired or very ill. This means that even quite severely impaired or unwell disabled people have a load of needs not met. There is a big division which leaves many people slipping through the net. So, if it (single trusted assessment) succeeds in bridging that chasm then that would be a very good thing."

"Also, at parts of formal medical assessment process you are allowed to be present but not to speak. At my last one, a nurse and social worker argued over my head about whose problem I was!"

The single assessment needs to come from a Social Model of Disability perspective and pass a 'real world' test. One person suggested three good questions, developed by Inclusion London, that could be used by assessors. They are:

- How do you want to live?
- What stops you living that life?
- What do you need to help you live that life?

A participant said: "I have several specialist teams and people working with me and each knows what they are doing within their own area of expertise. How will single assessors acquire the right skill set?"

"My needs are very diverse. How are they going to do this across different disciplines when they are all specialists? It's unicorn thinking! When I talk to my GP about complex impairment issues they say, 'I'm only a GP, I don't understand these things!' "

Another person made the point that: "assessments are not currently focused the idea that the disabled person knows the best about our own body and our own impairments. People don't trust us to know the best about ourselves."

The main recommendations from this group on the Single Trusted Assessment were that:

1. The assessment should follow a Social Model of Disability approach (i.e. the focus should be on removing barriers that stop the person fully participating in society)

2. It should be a 'real world test' (see suggested questions from Inclusion London above)

3. It should based on the presumption that the disabled person is the expert on their impairment and how it affects them.

4. The assessment should be co-designed with disabled people.

5. Training on the Social Model of Disability should be given to providers.

Definitions of the Social Model of Disability can be found at:

http://www.breakthrough-uk.co.uk/social-model-of-disability

and

http://gmcdp.com/information-2

*Participants asked for more detail on how the Single Trusted Assessment would work.

Impact of Independent Living Fund Closure
At GMCDP, there was also a related discussion on the impact of the closure of the Independent Living Fund (ILF) and funding for both social care and NHS continuing care:

"As the cuts bite, former Independent Living Fund (ILF) recipients need more support than councils can pay for. People who need more help are told to go to the NHS, but unless you're very severely impaired you're not going to get that. This could be really good progress but I can't imagine under austerity that this won't become attempt to cut funding."

"I had a fairly typical transfer from ILF to the council and they said instantly, before I'd had an assessment that there would be a one third cut and any difference from my former package is a medical need. There are 200 disabled people in Manchester in identical straights at least."

Experiences of accessing health and social care
People were generally positive about the local healthcare support they had received, especially intermediate care. For some people it was also the only social contact they got whilst they were recovering from a major event or illness. One person said that the holistic approach of his community health

provider made a huge difference when he came out of hospital. They assisted with shopping and managing the household as well as checking he was ok both physically and psychologically as he adjusted to living with impairment. This helped him feel much more confident and grounded.

Three people expressed a preference for home visits, and most survey respondents wanted this too.

Access to getting to, and within, healthcare venues was an issue for some people: "Better physical access. People not parking on pavements so I can go out safely". Also see the section on travel.

One disabled person said that the existing hubs where lots of health services are together are not fully accessible in their experience. For example, very few places in Manchester have really accessible toilets with hoists, including within hospitals. "The BEVC - where GMCDP and Breakthrough used to be - did have this. Day centres, for all their faults, do at least have them. Otherwise, you're stuffed."

A personalised approach from healthcare providers that is tailored to the individual and understanding of people's barriers was also highly rated: "With empathy. With consideration. By medical specialists who are aware of my illnesses and my care needs."

Taking time to explain things, check understanding and getting consent before any procedures were done all important to people who took part.

One person talked about their experience with the sensory team and a recent assessment change (Strengths Based Assessment?) where people are asked if they have other people who can support them: "They have been trying to get people you know to support you.", and say "We're not doing that because you have family". This person felt that the focus now is too much on "what support do you have" rather than on "what support do you need?". She said was happy with this herself, but was concerned for others who might not want their family involved in their support.

A clear message is that people want to be fully involved in their support, for this be tailored to the individual and for a person's wishes about who they want to be involved in their support be respected.

How people want to be treated by health and social care providers
People said:

- Listening is the most important thing. "Someone that will actually listen

to you and know exactly where you're coming from as a person."
- With courtesy and respect.
- With empathy, with consideration.
- Like I've got a brain.
- In a way that shows that they have a basic understanding of the Social Model of Disability.
- With transparency.
- With a 'real world' assessment.
- With a right to appeal.
- Like an equal.
- As an expert.
- With access to professional experts if need be.
- Not being taken advantage of (this person had experienced theft by a professional in their home)
- With advocacy, peer advocacy, peer support and co-production in place.
- Having people available to accompany me to certain appointments.
- Get me together with other teams and get things sorted with me there.
- Joined up working.
- By medical specialists who are aware of my illnesses and my care needs.
- Ease of Access
- Advocates are very important.
- Get things right first time – it's cheaper!

Eligibility Criteria
Changes to eligibility criteria for some services was raised at one workshop. Podiatry was given as an example. People have been told this is now only for people with diabetes. A participant said she could not manage to look after her feet because she couldn't reach them. Information is needed on changes to services and on what people's alternatives are.

One person said that self referrals would make access to healthcare provision easier to them.

Bureaucracy
We heard some powerful stories about disabled people struggling to get important things sorted out – things that directly impact on their independence. This was generally because of gaps in communication in the system. Examples of this are:

- One disabled person we spoke with in mid March has been waiting since October for a new concessionary disabled person's bus pass. His GP will no longer sign the bus pass forms and his consultant won't do it

either. He used to have a CPN but doesn't have one any more because of changes to eligibility criteria. He has personal assistance support from Age UK and is asking them to help sort it out for him, but doesn't know if they can yet.

- Another person has been waiting for 4 years to get a stairlift installed at home and is having to sleep in her front room in the meantime without access to the bathroom. She keeps getting passed from one person to another and has now, finally, been told that there is a waiting list, which she didn't know before.
- One young disabled person had identified a potentially useful treatment to help manage her condition and was trying to negotiate using her personal budget underspend to support travel to this. This is not being looked at supportively and the social worker is instead looking at day centre provision for her.

Participants want all staff they come into contact with to be aware of their history so that they don't have to start again with each new person. People were complimentary about practitioners who know them well, involve them and keep them updated.

Information

Information is critical. Participants at each conversation said that they don't know how to find out about things - and that doctors and other health practitioners often don't know what's available in the community, especially about health and wellbeing initiatives run by voluntary and community groups. Doctors also don't have much time to do this. Common comments included: "I don't know where to go, where to get information", and the need to be "Kept in the know about what's going on."

Talking about when she first developed her impairment a few years ago, one participant said:

"When I got ill, I didn't know where to go to, I didn't know what to do at all. I never had any involvement with social services or anything. So I just got passed from pillar to post. I had a pad at the side of me and it was full of numbers from different people who we spoke to, what they'd spoken to them, and it went everywhere with me.

For about a year and a half that was like my pad that I used to phone and then we'd be like, "Right, who do we need to phone today?" and it was literally like I couldn't concentrate on being ill. It was all about fighting to try and get help, so I didn't know what the process was, nobody came out and said this is the process, or they did come out and they didn't really go into it. It was like, "We'll pass you to this department…" I think things have improved

now."

There needs to be a system of communicating key information about the One Team, community resources, and rights to people who newly acquire an impairment.

People said they wanted someone knowledgeable on the end of a phone, not a 'customer service' rep. "Often when you ring the council you get someone who doesn't know. You need one point of contact and they need to be a genuine person who is informed and has the authority to act."

People often rely on peer support groups like Stroke Cafes to find out about things from other people in the same position. "I only find out what's available at these groups". People also said that medical staff don't always know what the different health related benefits they are on mean. At one group, someone mentioned that they were registered at a GP where there was social prescribing, and people thought this was an excellent idea.

One person who is very knowledgeable about her options and rights said that it shouldn't be down to her to know about what's available; this information should be known by professionals. She only found out recently about wheelchair vouchers, having paid a large sum for the one she currently uses. A booklet was suggested.

"People don't know where to get information". "To know what's there. Maybe one list online?"

People in the Breakthrough peer group said they would need support to know how to eat healthily, what to cook etc.

One older disabled person had been told that he could no longer use Ring and Ride because he was getting Disability Living Allowance. He didn't understand why. He did not know how to find out about what he was entitled to and what his rights were. He assumed this information would come from social services, but did not know who to ring there who could help.

People receiving benefits had experienced a number of issues. One person we spoke with was hit with an enormous council tax bill after starting low paid temporary work and found they didn't have enough to live on. Another person talked about a friend with cancer who had been found fit for work. Not everyone was aware of the advice available from the CAB or housing associations.

A Breakthrough client said it helps to know who to contact (for example a

named social worker) and how to do this. Often agencies don't contact him back. Another Breakthrough client agreed and said they would like to be called on a regular basis rather than having the onus on them to make contact all the time.

The accessibility of information was another important issue. An example was given where a social care team were critical because the participant didn't sign something they sent her in the post. The person couldn't access the print copy and asked for it electronically. This was not done so she was not able to access the information to sign it. They did not ask about what alternative formats would work for her. There needs to be a consistent approach to asking, recording and acting upon people's access requirements for information, in line with the requirements of the Accessible Information Standard.

One person said: "Lots of people don't know about the Accessible Information Standard in the NHS (and social care!) and it's not being implemented even though it's already in force."

Only about half of the people we spoke with are online (and this tallies with our experience at Breakthrough more generally). Communication with disabled people must be targeted in other ways. Having everything on the internet only is not accessible to a lot of disabled people.

Peer Support
Peer support was a very strong theme coming out of all of the group conversations. It enables people to take more control of their health, find out what their options are and be in an environment where they are understood without judgement. People felt that such groups were a lifeline and needed to be well resourced. Participants also said that they were very good for their mental wellbeing too "it lifts your spirits coming here".

Many disabled people we spoke with said they were/had been isolated and struggled to meet people. Some of these people now attend a Breakthrough peer group. They said that this was making a huge difference to them in terms of social contact, getting information and managing anxiety.

One person in that group said that they did not have any friends and there were no activities he could take part in where he lived in South Manchester. Another young disabled person said he had been too anxious to leave the house for 6 months but was now feeling much more confident because he had somewhere safe to go to talk about issues and meet other people experiencing the same things and "on my wavelength".

At a meeting with Stroke survivors, one person talked about the difficulty getting information on the peer support available: "and if you speak to social workers, if they're not aware of what's out there, then they can't then say, "There's this stroke group that you could go to." It is a lifeline. If you ask everybody there at the group they'll all tell you it is a lifeline for a lot of them. A lot of them don't get out apart from going to the stroke groups, do they?".

Access
Issues with accessible toilets not being adequate have already been highlighted. Another point raised by participants is the lack of understanding of what constitutes a fully accessible venue. It's not enough for a venue to say it's accessible, they often aren't when arrived at. "You might go somewhere and they say it's accessible but it's not completely accessible."

"As long as they've got a ramp they think it's accessible but they don't see other things. Or they've just got a handrail in the toilet and think that's an accessible toilet, which it clearly isn't."

One group felt that a good option would be for disabled people to peer review venues (along the lines of the www.disabledgo.com model).

Communication
Communication was another big area of concern when dealing with health services, although some people thought things were improving on this front:

- Several disabled people said that referrals to social services had broken down because of poor communication, lack of follow up, phone calls not returned and in one instance, refusing to give out a phone number for a team to someone who couldn't access the internet.
- Participants want to be listened to. People said more training on appropriate, respectful communication is needed for health and social care professionals. Some people at the Stroke Clubs with Aphasia felt that they were rushed and not always spoken to respectfully or directly: "but if I didn't have the stroke you wouldn't talk to me like that because I would have fired it back at you. But because I've had the stroke I'm very careful of what I say to people and I don't want to be careful, I just want to be a person who can let rip without having to cry afterwards when I put down the phone or when you've left me."
- One person was unable to get a same day GP appointment, as specified in her care plan, because reception staff either didn't know about this or didn't follow the plan.

Attitudes

Much of the above is linked into attitudes towards disabled people, which many disabled people experience as increasingly negative. A disabled person we spoke with at one of the drop-ins told of how he is continually on the receiving end of hostile name calling. He believes this is because of his appearance. He is now scared to go out and doesn't feel that the police are interested (we talked about his reporting options). He also feels that there is nowhere safe to go to meet people in Wythenshawe, especially if you are older.

Several people noted that attitudes towards disabled people have deteriorated in recent years. This was mentioned in particular at the last two workshops.

One person said she had noticed a big change in attitude towards her since she became a disabled person: "I find that the outside world is really, really vicious. You don't notice it until you actually become ill, and once you become ill you're wondering what kind of world are we living in."

"That's how I found since I've had the stroke when people are talking to me, I go within myself and I feel really small and I don't want to feel like that because I am someone."

One participant also reminded the group that "the worst stuff is not always the most obvious."

In relation to tackling attitudinal assumptions, the suggestion was training: "They need to go and talk to people". Health and Social Care staff need training on their own assumptions, for example, how have these been affected by what they see in the media?

Funding for social care

One disabled person said that she was just about able to manage with the limited support she gets with personal care from an agency, but there isn't enough time allocated to assist her with all of the other things she needs. She accepts this and tries to manage. Her friend is an older disabled person who gets no support because she is a self funder. Her friend doesn't know what's available or what she might be able to access. Points have been made in other sections about direct payments not covering people's health, wellbeing and independent living requirements, and about serious shortfalls in funding for former recipients of the ILF.

Funding for Voluntary and Community Groups
One person at a workshop with Stroke survivors talked about inconsistent provision across different areas of Manchester. Some areas of the city have more funded resources for Stroke survivors than others.

Another group said that people shouldn't be passed on to charities who do not have the resources or sustainable funding to assist them.

Travel
Travel and transport to healthcare venues was raised as a key issue in all of the conversations, and therefore health and social care being available in accessible local venues was very welcome.

- Free bus pass use only kicks in for most disabled people after 9.30am on weekdays (and stops again 3.30pm to 6pm). Some GPs surgeries expect people to queue outside from 8am to get a same day slot (an issue in itself). One older disabled person reported using a taxi to get around this, something she struggles to afford.
- Ring and Ride have had their budget cut, face more cuts, are not reliable, forget bookings and do not communicate well about what they do and who they support. It is not seen as a viable option for getting to healthcare appointments.
- Travelling for some people is dependent on the availability of others to accompany them to offer assistance. One person who employs a personal assistant said that travelling to appointments often has to be managed around her PAs limited working hours. Appointments need to be flexible to accommodate this and as local as possible.
- Funding is not sufficient for peer and condition management groups to always pay for transport for people who cannot access public transport. "We have to rely on people to take us".
- Taxis are expensive. A lot of people don't know about taxi vouchers and how they can be used.
- Some disabled people talked about problems with driver attitudes: "Sometimes they don't pick me up. I don't tell them any more that I'm in a wheelchair, because if I tell them they don't turn up. My chair half folds but not completely down so I always say make sure it's a bigger boot to fit it in. The guy that picked me up, I was at the hairdresser's and I was waiting ages. I said, "I've been waiting ages for you," and he goes, "Oh, yes, you got a call through but everyone declined it because you're in a wheelchair, they don't want to carry your chair into the boot."
- There are no talking buses in Manchester so people with visual impairments are relying on drivers to co-operate and tell them when to get off. Not all do and one person faced a 20 minute walk recently because the driver refused to stop after he passed his stop without announcing it.

- Bus driver attitudes are a problem generally and they need disability equality training.
- People were happier with the accessibility of trams, but they do not service all parts of the city.
- One person suggested that the proposed re-regulation of public transport in Greater Manchester might resolve at least some of the issues people are having.

Accessing leisure facilities

A young disabled person, fairly recently arrived in South Manchester, spoke of her frustration at the lack of accessible leisure facilities, gyms particularly, that she could use. She said that most venues say that they are accessible on the website, but when she gets there she finds that there is not enough space at the gym for her wheelchair. Because the online information is unreliable - and staff often don't know enough about access - she finds that she has to go out to each venue in person to assess them herself, which is very time consuming and costly. This impacts on her ability to stay fit.

Another disabled person who is trying to find a suitable gym said he was turned away from one on health and safety grounds and that the staff would not help him fill out the application form - which was not accessible to him in paper copy because he has a visual impairment. He needs to find something that is low cost as he is currently seeking employment and these options are limited. Another person said that they don't go to their local park because it is not accessible and it doesn't feel safe.

At one session, participants were advising each other on how to make the best use of gyms. One person with a visual impairment is a very regular gym user. She said that it's important to build up a relationship with a personal trainer there and ask them to give you guidance on all the equipment, including accessibility. Her trainer has given her the detailed layout of the gym she uses and this has massively increased her confidence about using the gym overall. He also mentioned to her that he regularly sees disabled people who only use one specific piece of equipment in the gym all the time because they don't know about their other options.

Employment discrimination: Two people at drop-ins spoke about potential employment discrimination (within work) and wanted to know what their options were. One disabled person said that their employer had not made any adjustments for them and felt they were being pushed out of his job because he couldn't do some of the physical aspects of it. We also heard about a young disabled person who had been dismissed from an apprenticeship for issues that would have been avoided if reasonable adjustments had been made. Both had declared to their employer that they are disabled people.

Again this potentially links to poor enforcement of the Equality Act locally and the need to link employers up with organisation like Breakthrough who can offer support and advice.

Recommendations

Engagement

Engagement with the public on the One Team approach and 'A Healthier Manchester' is not reaching many disabled people, many of whom are not online.

Information on key changes should be cascaded through disabled people's organisations, existing meetings and through all the local groups linked into Community Explorers Meetings.

Alternative formats need to be clearly available, with standard print Word versions also distributed electronically so that groups can create their own copies and formats as required.

A 'piggybacking' approach to engagement where information is shared with existing groups of disabled people works better than arranging stand-alone meetings in our experience.

Information

There needs to be a better system of communicating key information about local community resources, advice, and key rights around independent living disabled people. This is especially important to people in the city who newly acquire an impairment. Historically, this work has been done by disabled people's organisations, but many are lacking capacity to do this at present.

This system should be co-produced with disabled people. It could link up well with the 'asset mapping' work already taking place in the city which Macc are pulling together. There is a need to ensure that the outputs of this asset mapping are fully accessible.

People we spoke with were largely in favour of an informed and accountable 'one stop shop' approach, particularly for queries related to health and social care. This needs to be available through a variety of media to ensure accessibility.

Team Communication

Disabled people gave lots of examples of communication breakdowns between teams involved in their support. Good communication between health and social care teams is already a core component of the approach in principle. Close monitoring is required to ensure this is happening in practice.

Peer support

Peer support is hugely important to disabled people's health and wellbeing. This was a very strong message from all the conversations. These groups – whether hosted by disabled people's organisations, impairment specific groups or via patient experience models, need to be supported and resourced.

Training

Equality and Diversity Training for all providers working in the new structure must include action training on barrier removal and the Social Model of Disability. Attitudes / assumptions and inclusive communication are key areas to focus on. We recommend a disabled person's organisation is commissioned to deliver this aspect of E&D training.

Legal Enforcement

The anticipatory duty of health and wellbeing related service providers to make reasonable adjustments under the Equality Act needs more robust enforcement. This is already statutory duty for health and social care providers, alongside the Accessible Information Standard. EDS2 is one lever Manchester Health and Care Commissioning can use to increase compliance, but would not be applicable to all community wellbeing and leisure providers.

We recommend a) awareness raising on the nature of adjustments required by most disabled people and that they are rarely costly and b) demonstration of compliance by providers before contracts are awarded.

The Accessible Information Standard must be implemented fully across all statutory provision. There needs to be a consistent approach to asking, recording and acting upon people's access requirements for information, in line with the requirements of the AIS and to perform well under EDS2.

All Age Disability Strategy

As the approach develops and moves into new arrangements with the Local Care Organisation it is very important that all work links up with the cross cutting All Age Disability Strategy (AADS) in Manchester, which has a very strong focus on the 12 Pillars of Independent Living. There are senior NHS and council representatives on the AADS Partnership Board and the AADS gives opportunities to work with providers across the city to level up good practice on all pillars of independent living through several thematic subgroups which include 'Health and Care', 'Inclusive Communities and Transport' and 'Information, Communication and Digital Inclusion'. The 12 pillars of Independent Living are:

- Appropriate and Accessible Information
- An adequate income
- Appropriate and accessible health and social care provisions
- A fully-accessible transport system
- Full access to the environment
- Adequate provision of technical aids and equipment
- Availability of accessible and adapted housing
- Adequate provision of personal assistance
- Availability of inclusive education and training
- Equal opportunities for employment
- Availability of independent advocacy and self- advocacy
- Availability of peer counselling

Advocacy

Disabled people need to know more about their advocacy options and the work of the Manchester Advocacy Hub needs stronger promotion. This statutory advocacy will not meet all needs however, and consideration should be given to commissioning and supporting work which enables disabled people to develop skills to self advocate in health and social care provision.

Carers

One group recommended that there should be something in place to ensure that carers are not involved, either in the assessment process or in information sharing. More information on how disabled people can refuse consent to carer's involvement needs to be provided.

Single Trusted Assessment

The term needs to be qualified so that it is not assumed to include welfare benefits assessments.

Consider adoption of Inclusion London's three questions into the Single Trusted Assessment process:

- How do you want to live?
- What stops you living that life?
- What do you need to help you live that life?

Further points on the Single Trusted Assessment:

1. The assessment should follow a Social Model of Disability approach (i.e. the focus should be on removing barriers that stop the person fully participating in society)

2. It should be a 'real world test' (see suggested questions from Inclusion London above)

3. It should based on the presumption that the disabled person is the expert on their impairment and how it affects them.

4. The assessment should be co-designed with disabled people.

5. Training on the Social Model of Disability should be given to assessors.

ILF

Although beyond the scope of this work, there have been calls from disabled people's organisations for the new Greater Manchester Mayor to set up a localised version of the Independent Living Fund. This would resolve some of the issues raised by disabled people we spoke with.

Access

Set up an accessible mechanism for disabled people to peer review health, social care and wellbeing related venues (i.e. www.disabledgo.com model but with offline options to input and retrieve information.

This would also help with engagement work – a list of accessible, low cost meeting venues across the city regions, co-produced with disabled people, would be an incredibly useful asset.

There is scope for a piece of work around disabled people and leisure facilities / gyms – disabled people who use facilities and staff/trainers sharing good practice and advise on how to make the most of facilities and increase accessibility.

Contact

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