#SpeakUp small grants programme

2021-22 Summary report

Background

What is #SpeakUp?

#SpeakUp is our small grants scheme, aimed at local not-for-profit, community and voluntary sector groups. The grants (typically from £500-£1000) help to fund projects which gather the views and experiences of local people in relation to health and social care services. We've funded 35 projects since launching the grants scheme in 2018, ranging from focus groups, community fun days, shared meals and more.

Once organisations have carried out their activities to help them hear from local people, we help to write up their findings. We work with them to make recommendations to improve local health and social care services, and make sure these reports are seen by those who can make change happen.

By working with groups who are already trusted partners in their communities, we can make sure we're hearing from even more people, including those whose voices aren't often heard by services.

#SpeakUp 2021-22

This year, **12 groups carried out #SpeakUp projects**. Altogether, **they heard from around 790 people**.

The groups who carried out projects were: SACMHA Health & Social Care; Asperger's Children and Carers Together; Autism Hope; Luv2MeetU; Burton Street Foundation; Sheffield Voices; Saalik Youth Project; Pitsmoor Adventure Playground; Burngreave Messenger; South East Sheffield Community Dementia Advice Service; JCI Sheffield; Sheffield Maternity Co-operative.

Understanding the summary report

This year we heard about a wide variety of topics, from many communities in Sheffield. This report provides a snapshot of what each grant recipient organisation did and their key findings, as well as exploring cross-cutting themes that emerged from the projects. Each project did result in its own individual briefing, which you can find links to in the appendix. We would encourage those working with specific communities to read relevant reports in full.

790

people shared their experiences through this year's #SpeakUp projects

Contents

What did people tell us about?

Cross cutting themes:

African Caribbean perspectives on home care

SACMHA Health & Social Care is a charity delivering a specialist service to people in need of assistance with their health and social care needs. The organisation has its genesis in the African Caribbean community and still has a specialism within that community.

This year Sheffield City Council have been reviewing home care services in the city, and making plans to improve them. Hearing from local people who use home care is crucial to making sure their plans are the right ones, and SACMHA wanted to make sure that African Caribbean voices were heard as part of this process.

Who did they speak to?

SACMHA talked to 19 people about their experiences of care; service users, families/ carers, and social care professionals from the African Caribbean community.

What did people say?

- **Factors that can make care a positive experience**: These included employing Personal Assistants (PAs) via Direct Payments, PAs coming from the same cultural background as clients, and people being able to become familiar with their carers over time.
- **Issues involving staff behaviours**: People spoke about inexperienced staff, or staff who were not caring or respectful. They also spoke about staff who did not or were not able to provide individualised care.
- **Practical challenges**: There was a lack of adequate time allocated to some tasks, which meant care visits were rushed. People also spoke about challenges involved with finding and recruiting PAs, with complex admin and difficulties finding holiday and sickness cover.
- **Poor communication**: Some people said agencies don’t listen to personal preferences relating to care, delays and changes to care calls are not communicated, and clients and family members have to ‘chase up’ agencies when things go wrong.
- **Lack of culturally appropriate care**: there are too few carers from different cultural backgrounds, and carers don’t always take the time to understand the cultural needs of an individual.
- **Finance**: costs of care are unclear or prohibitive, acting as a barrier to care.
- **Training**: there is not enough (mandatory) training in providing empathic, person-centred care, and a lack of training to work with diverse communities.

Experiences of diagnosis & support for children with Autism

Asperger's Children and Carers Together (ACCT) is a parent and carer-led support group for autistic children and young people and their families in Sheffield. **Autism Hope** are a support group for parents and carers of children with autism, based in North Sheffield.

Both of these groups wanted to use their #SpeakUp grants to amplify the voices of families of children with Autism. ACCT largely focused on accessing support in school, while Autism Hope focused more on getting a diagnosis and accessing health services.

Who did they speak to?

Between the two groups, we heard from 138 parent-carers. Their children all had autism; many also had other Special Educational Needs or Disabilities (SEND), and additional mental or physical health conditions.

What did people say?

- **Getting a diagnosis:** Parents from both projects spoke about lengthy waiting lists for assessment and diagnosis. Many said that this delayed getting the right support in place for their children, both in terms of relevant referrals to other health providers, and in terms of support in school/education.
- **Support from health and social care services:** The parents who spoke to Autism Hope talked about their experiences with a lot of different health & care teams. Where people spoke about positive encounters, this was largely down to helpful individual staff members who really helped their family. Most of the experiences we heard about were less positive, and centred on long waiting lists, lack of timely onward referrals, insufficient levels of support, and not feeling like they were being listened to or taken seriously.
- **Support in school:** The parents who spoke to ACCT talked in detail about their children's experiences of support in nursery, school, and further education. They found that the processes in place are difficult - for instance applying for Education, Health and Care Plans (EHCPs) – and that the available support is not always appropriate for their children's needs.
- **Peer support & support for parent-carers:** Both groups found that peer support is invaluable for parent-carers, as is the information-sharing that this often involves. Outside of peer support groups, many parents reported not feeling they could access support out of fear of being judged and deemed 'bad parents'.
- **Fighting for support/not being listened to:** Parents in both reports talked about having to 'fight' for the right support for their children; they said they have not been listened to by professionals, have had their parenting blamed for their children's behaviour, and are not supported to access the right help.

Experiences of adults with a learning disability

Burton Street Foundation is a community organisation which provides a range of day services for people with learning disabilities. **Sheffield Voices** is a self-advocacy group made up primarily of adults with autism and/or a learning disability. **Luv2MeetU** is a friendship and dating organisation for adults with autism and/or a learning disability, organising activities and social opportunities.

All of these groups used their #SpeakUp grants to explore different aspects of life and care for adults with a learning disability, particularly focusing on how things have changed since the beginning of the pandemic.

Who did they speak to?

Luv2MeetU and Sheffield Voices heard directly from **33 people** with a learning disability about their experiences. Burton Street Foundation spoke to the families/carers of people with learning disabilities, hearing from **152 people**.

What did people say?

- **Annual health checks:** Burton Street found that most people with a learning disability are being offered an annual health check, and are taking these up, but there are still barriers to accessing them, so professionals need to be proactive.
- **Hospital passports:** Burton Street found that this resource was not used as widely as annual health checks; people did not have confidence that hospital staff would use them and some needed help in order to fill one in.
- **Access to other health & social care services:** Luv2MeetU's members spoke about accessing health services such as GPs, dentists, and mental health care. Around half were not confident in accessing the care they needed by themselves, and those who were had found it difficult to get in contact with services during the pandemic. People were largely happy with the care and support they did receive, but would like to be given the information they need to understand what's available.
- **Concerns about disabled people during the pandemic:** Sheffield Voices members spoke extensively about their concerns about the disabled community throughout Covid-19. They said that disabled people's voices hadn't been listened to about a wide range of important topics, from lockdown restrictions and face coverings to safety issues within services for disabled people.
- **A desire to be more independent:** Luv2MeetU's members shared a real desire to be more independent, which included being more involved in managing their own health and wellbeing. For instance, they requested additional support to get out into the community, as well as information and classes about health topics like nutrition, cooking, and mental health.

Children, young people and families in Pitsmoor, Burngreave & Fir Vale

Saalik Youth Project works with young people aged 6-25 from ethnically diverse backgrounds in Pitsmoor, Burngreave and Fir Vale. After working with us to explore aspects of their own health, the group's young people wanted to explore the impact Covid-19 had had on their communities.

Who did they speak to?

The young people surveyed 221 other young people, and 86 parents.

What did people say?

- **Worries about lockdown and school:** Young people's main worries about Covid-19 were focused on not being able to leave home, and a lack of exercise/physical health. Parents mostly worried about the mental & physical health of themselves and their children, as well as about the disruption to their children's education.
- **Who would people go to for support?** Young people and parents would both prefer to go to friends and/or family members for support or advice if they were worried. School staff, youth workers, and health professionals all ranked much lower, hinting at a lack of trust in statutory organisations. This needs to be addressed if everyone is to have equal access to support.
- **What support would people want in the future?** Young people said they would like to have access to more trips, sports/fitness sessions, and social/charity projects. They also wanted workshops to better understand important issues for them, such as gun/knife crimes & violence, finance skills & money management, and health. Parents wanted greater support with fitness & sport too, as well as being able to access religious workshops and mental health awareness courses.

Two other organisations also ran projects working with people in Pitsmoor and Burngreave. These focused less on gathering feedback, and more on providing information and raising awareness about health and wellbeing:

- **Pitsmoor Adventure Playground** offers play opportunities which support children and young people to improve their health and wellbeing, learn new life skills and become active citizens. They used their #SpeakUp grant to speak with around 20 children about their awareness of health and wellbeing. They talked about looking after their senses (awareness of hearing and eyesight), eating healthily, looking after their teeth, being happy, and staying active.

- **Burngreave Messenger** is an independent community-based newspaper, delivered free to over 9000 households in the Burngreave ward. They used their #SpeakUp grant to dedicate pages in several issues to health and wellbeing topics, and encouraged local people to share their experiences of health and social care. Topics included information about lockdown, vaccination, online activities, exercise, and peer support.

People living with dementia and their families/carers

South East Sheffield Community Dementia Advice Service supports people living with dementia and their families/carers, linking them in with local activities and opportunities. They used their #SpeakUp grant to ask people what additional support they might need.

Who did they speak to?

Conversations were held with 10 people living with dementia, and 28 family carers.

What did people say?

- **Covid-19 had made existing challenges even more difficult**. This was especially true for people living in care homes, where separation and isolation had been hard, and sometimes made dementia symptoms worsen. People also found it more challenging to access support services during the pandemic.
- **Navigating the health and social care system needs to be easier.** People would like to see a 'one stop shop' where they can get advice or recommendations about services. They would also like to see families involved in care from an earlier stage, and more support given to families more widely.
- **Communication and information provision needs to improve,** including better communication with individuals and families, face to face appointments, and the opportunity for real conversations instead of being provided with leaflets.

Young professionals managing their mental health

JCI Sheffield provides development opportunities for young professionals. They used their #SpeakUp grant to speak with their members about looking after their mental health.

Who did they speak to?

JCI Sheffield spoke with 22 people via surveys and short interviews.

What did people say?

- **Different approaches work for different people**: This includes formal mental health support (talking therapies, medication etc) as well as informal support and self-management techniques (peer support, creative hobbies etc).
- **What works for an individual can change over time**, and people may need to adjust their approaches to self-management and formal support regularly.
- **People need choice and control over their support options**, and the opportunity to explore different approaches to see what works for them.

People accessing maternity services

Sheffield Maternity Co-operative are a collective of midwives, birth workers and people who want to build and support better care and community for pregnancy, birth, postpartum, abortion and loss. They used their #SpeakUp grant to host a series of creative workshops, which resulted in an online Zine as well as a report.

Who did they speak to?

60 people attended across 6 workshops, including poetry, collage and sculpture.

What did people say?

The creative pieces themselves, and the conversations that the workshops held space for, gave Sheffield Maternity Co-operative many insights into how maternity services could improve, including:

- The provision of clear information, especially for first pregnancies and when Covid-19 restrictions are in place
- A need for increased post-natal support
- The importance of people not being left alone whilst in labour, and being given adequate pain relief
- A need for more culturally competent support, working more closely with relevant community organisations

Cross cutting themes

Challenges facing carers

Several projects spoke with people who care for family members, and identified similar challenges. Asperger's Children and Carers Together (ACCT) and Autism Hope both spoke with parent-carers of children with autism; individuals from both groups spoke about accessing support for their children being a 'battle', and feeling that their hard work was the only reason their children finally got support.

Family carers of people living with dementia also felt that accessing support for the person they cared for was challenging, and they didn't feel supported as a carer by the services they were reaching out to.

> *"I don't feel I have the energy to battle for these things for my daughter"* - Autism Hope
>
> *"I have to do everything myself. There must be a better way"* - Sheffield South East Community Dementia Advice Service

SACMHA Health & Social Care's project provided some insight from family carers too. They spoke with members of the African Caribbean Community who use adult social care services and their families. They found that it was often family members having to support in getting care services organised, and 'chasing up' services when things went wrong, and this was identified as a challenge.

The other major challenge identified by family carers was the difficulty of accessing support for themselves. Most people who spoke to Autism Hope said they hadn't received any support for their own wellbeing and mental health - they talked about health professionals not proactively reaching out to offer them support, and practical challenges to accessing support (including time and money). Fear of stigma was another significant barrier - some carers felt that reaching out for support would lead to judgement.

> *"I had my parenting skills judged and blamed before he got a diagnosis so I was scared they would think it was my fault after all"* - Autism Hope
>
> *"Fear of being branded a bad mother. Kids taken off you"* - Autism Hope

Need for clear information

Several groups identified a need for clear information about what support is available, how to access it, and support accessing it if necessary. Clear information may mean different things for different people, depending on their individual needs.

For example, Sheffield Voices and Luv2MeetU identified a need for more accessible information for people with a learning disability or other communication need. Sheffield Voices identified specifically that information about Covid-19 restrictions was not very accessible to those who used British Sign Language.

Luv2MeetU focused on information being provided in Easy Read formats. Their group members would like a booklet with information about health and social care services - what different services do, what they can access, and how to contact them.

> *"Media/gov information not accessible, no signers on the news […] people who use sign language were not being cared about"* - Sheffield Voices

As well as a need for Accessible Information, we heard from other groups who felt that information about what was available or who to contact was generally difficult to find or difficult to understand. People at Autism Hope and ACCT said they needed more information about what support is available for children with autism. Parent-carers from both groups relied on peer support and sharing information between themselves – they felt this was invaluable but statutory services should also be filling these gaps.

People who spoke to SACMHA said that the costs of care were difficult to understand and sometimes put people off accessing services. They also wanted to see clearer guidance to support people who were employing their own Personal Assistants (PAs) as finding an appropriate person, then organising finance, holiday coverage etc is complex.

> *"There isn't a database of PAs so people need to rely on personal recommendations and word of mouth"* - SACMHA

Sheffield Maternity Co-operative and South East Sheffield Community Dementia Advice Service highlighted the need for clearer information for individuals and their families when visiting services (hospitals and care homes respectively) – these services had strict Covid-19 restrictions, which changed regularly and staff sometimes gave conflicting advice, which made things more difficult for people to understand.

Some people wanted to be given information in more interactive ways. People who attend Luv2MeetU meetings would like to attend workshops on different aspects of health and wellbeing, such as cooking healthy meals. This would help them to feel more in control of their own health. The people that Saalik Youth Project spoke to (young people and parents living in Pitsmoor, Burngreave and Firvale) also wanted to access workshops on health and wellbeing topics ranging from drug use and crime, to nutrition, and religious workshops.

Difficulties navigating the system

Many groups identified challenges that the people they spoke to were having when trying to navigate through the health and social care ‘system’. This relates to the need for clear information about what support is available and how to access it (see the section on ‘need for clear information’ above) but also additional challenges people faced trying to get that support, even when they knew where to start.

South East Sheffield Community Dementia Advice Service and Luv2MeetU said that finding out who to contact can be hard, but even when you do know who to contact and how to do so, getting through to speak to someone on the phone can still be really difficult. SACMHA’s project raised similar concerns, saying that families were having to spend a great deal of time chasing up services about problems with care or arranging more care.

> *“Can’t always get an appointment and can be tricky to get there”* - Luv2MeetU

Autism Hope, ACCT, and South East Sheffield Community Dementia Advice Service all identified waiting times for assessments and referrals as an issue too. Some waiting times are very long, and there isn’t always interim support available or information about how long a referral is expected to take, leaving people feeling *“left on my own”* while they’re waiting.

Need for culturally competent care

Several projects identified a need for more culturally appropriate care. Saalik Youth Project found that the young people and parents in their community would speak to family and friends about issues they were facing, much more than they would speak to health professionals or school staff. There was a lack of trust in statutory services, which must be addressed in order to properly engage with this community, and deliver the services they would like to see (such as the workshops described in the 'need for clear information' section).

SACMHA identified that when families have had good experiences with Adult Social Care, it is often because a carer comes from the same cultural background as them and can understand their needs. They want to see a more diverse workforce to make this more widespread, and said that a lack of culturally appropriate care could lead to individuals dropping out of the service.

> *"Not enough time invested in understanding […] what is important to them e.g. clients saying they do not want care when they experience care they feel may be culturally inappropriate or uncomfortable for them and this could lead to a case being closed unnecessarily" -* SACMHA

Sheffield Maternity Co-operative spoke about black and Asian women having different birth experiences to white women, pointing specifically to differences in pain medication based on ethnic or cultural stereotypes. They would also like to see a greater recognition that birth is a significant cultural experience as well as a medical one; people from different cultures may wish to mark this in different ways. They would like to see health professionals work more closely with organisations who can offer this cultural support to pregnant people and their families.

Continuity of care and building relationships with key professionals

For many groups, being able to build a good relationship with health and social care professionals is key to a positive experience. We can see this in Adult Social Care, when people who spoke to SACMHA had better experiences when their carers were known to them and the same people came regularly. We can also see this in primary care – Burton Street Foundation spoke to professional carers and family carers of adults with a learning disability, who said that one of the key benefits of Annual Health Checks was building a relationship with their GP. Where experiences of Annual Health Checks were less positive, a key factor was having to see a different professional each time. In maternity care, this was identified as an area for improvement, with Sheffield Maternity Co-operative calling for greater continuity of care for families.

> *"Really good doctors. Really good practice nurse. Always available. Known [her] since she was a baby"* – Burton Street Foundation

These strong relationships are equally important for community or voluntary sector organisations, and statutory organisations could learn from where community groups have done this well. Pitsmoor Adventure Playground said that by working with children and families over a greater period of time, they have built trust and feel more able to speak with them about health and wellbeing topics, which might have seemed like sensitive topics when the relationships were new. The same is true for the young people that Saalik Youth Project works with – they are happy to speak to workers there openly about many issues, which they may not be as comfortable discussing with other professionals.

“Building stronger relationships with the children and their families allows us to spark particular conversations as we know more about their lives and interests” – Pitsmoor Adventure Playground

Desire to be involved with service improvement

All of the #SpeakUp projects aim to connect individual service users and carers with decision-makers, by sharing their feedback and experiences through our reports. Several projects revealed that many individuals were also keen to be involved in service design and monitoring in a more direct way. Parent-carers at Autism Hope and ACCT, and people with lived experience of disability at Sheffield Voices, would like to be consulted more about the services they use, and have direct input into shaping services.

Autism Hope and ACCT pointed out that carers have a wealth of knowledge about how services work, as well as gaps in services, that could be extremely useful to commissioners. They would like to see engagement with carers embedded into health and social care systems, so that feedback based on lived experiences can drive real improvement.

“Both in individual cases and on a system wide level, services should work to improve and develop the way they listen to the voices of parent carers” - ACCT

Sheffield Voices members were also very clear about the importance of involving individuals with lived experience in decision-making, as well as the monitoring of services. They said that service users are often the first to raise concerns when things go wrong, and if they are listened to at the outset then improvements could be made. However, they said that currently the voices of disabled people aren’t being listened to, in both individual cases and on a more system-wide level. In the worst instances, this can lead to abuse or other harm.

> *"It's really bad what's happened in places like Firshill, people haven't had their voice heard and things have gone unnoticed"* - Sheffield Voices

Communication between services

We heard from some groups that different health and social care services could work better together, communicating about an individual's care in order to make it easier to navigate. This is especially true where people might be accessing a large number of services; for instance the parent-carers who spoke to Autism Hope had accessed on average seven services to support their children, and believed that if services worked better together and they only needed one main point of contact, their support would be easier.

> *"There should be one medical system which all services can access. Each service can then see input from other services and treatment can be more specific and tailored to each individual"* - Autism Hope

South East Sheffield Community Dementia Advice Service reported a similar need, with individuals they spoke to asking for a *"one stop shop"* for practical support as well as listing *"vetted"* service providers, as separate services don't always work together well for individuals. Luv2MeetU members said similar, asking for an *"easy person to reach to ask simple questions or if something was worrying me."*

Communication from services to individuals and their families

We heard from most groups that communication between health and social care services and individuals receiving care was not always timely or appropriate.

SACMHA learned that social care services and individual professionals were not always communicating well with clients and their families, which led to a lack of personalised care. The people they spoke to raised instances where professionals, whether due to lack of time or lack of adequate training, didn't listen to people's preferences about their care, or accommodate their needs in relation to religion.

Proactive communication, and communicating with people in the right way for them, is also key. Burton Street Foundation found that many families/carers of adults with Learning Disabilities weren't sure whether their latest Annual Health Check had been delayed – suggesting that they do need that proactive contact from services to make sure they're making use of available resources.

The importance of community

The importance of community also arose from several reports. Even though most groups were asking questions to better understand people's relationships with statutory services, people also began speaking about other sources of support they relied upon or valued. The importance of feeling that one belongs to a community came out of some conversations very strongly.

When Luv2MeetU asked their members who supported them, people did refer to care professionals, but also family, friends, and partners. Sheffield Voices members did too, as well as speaking about how neighbours have helped them, and the importance of belonging to community groups. These groups aren't necessarily peer support groups – they might be centered around a hobby or interest instead - but they provide support for the individual nonetheless. We see the importance of community, too, for the young people and parents that Saalik Youth Project spoke to. They would not necessarily approach health or care professionals for support, instead turning to friends, family, and religious leaders.

> *"Good Zoom community – being able to talk to other people when needed"* – Sheffield Voices
>
> *"Less than half of the parents we spoke to would go to a health professional for support for them or their children"* – Saalik Youth Project

However, many groups were clear that while community and peer support are invaluable, formal statutory organisations should also be working to address any gaps. They want everyone to have equal access to information and support, not just those who are able to access communities that can help them. Saalik Youth Project recommended that statutory organisations consider ways to improve their relationships in communities where there is a lack of trust, and ACCT would like to see the benefits of peer support embedded in a way that could support a greater range of families.

> *"Peer support, while valuable, should only be a complement to 'official' information and support given through mainstream channels, not a substitute"* - ACCT

Recommendations

Working with the grant recipients, we identified areas for improvement for health and social care services and made relevant recommendations.

Most reports have their own individual recommendations, but where projects had significant overlap we have grouped them together below, for ease of health & social care commissioners and providers who work with particular communities. We would, however, encourage people to read relevant reports in full and consider all of the recommendations they make.

African Caribbean perspectives on home care

There were a number of recommendations made in the SACMHA report relating to Adult Social Care. We haven't listed them here as they are now being addressed via an action plan by Sheffield City Council. If you want to read more about this project, read the report and the follow up on our website.

Experiences of diagnosis & support for children with Autism

1. Assessment and diagnosis -

1.1 Parents, who are often the first to notice signs of Autism in their children, should have a clear route to raise this.

1.2 Waiting lists for diagnosis are unacceptably long. Local health and care bodies (CCG, SCC, SHSC) should consider how resources can be made available to reduce waiting times. If this is not possible within local resources, city leaders should be making strong representation to central government on this issue.

1.3 While waiting for assessment, children are missing out on vital support. Interim support should be offered and tailored to individual need.

1.4 Statutory organisations should review information they share along the diagnosis pathway to ensure that it is clear, accessible and actively shared in a timely way.

2. Services -

2.1 Systems for better information sharing between the various teams involved should be developed to improve communication.

2.2 Services should take note of feedback raised in the Autism Hope report, which contains detailed experiences of specific services – to respond, and to consider how to make their own feedback routes more accessible to parents.

2.3 Autism training to be mandatory for all health and care staff working with children and young people.

3. Support for parent-carers –

3.1 Few parent-carers we spoke to were accessing formal support, but many report feeling stressed, exhausted, or overwhelmed. Support needs to be more pro-active – consider where services can reach out to parent-carers to offer support and/or signpost to support.

3.2 Feeling judged is a barrier to accessing help – messaging from professionals needs to directly tackle this to reassure parents that they are there to support, not judge. They should be mindful of this in all interactions with families.

3.3 Increased respite options for parents need to be developed.

4. Education –

4.1 Improved support (pro-active and tailored to the family’s needs) to help families navigate through education – e.g. support to understand ECHPs, and good information about transitions to secondary school.

5. Involving parent-carers –

5.1 Parents of children with autism have a wealth of knowledge and experience which could help drive improvements, both in individual cases and on a system wide level. All services, including Schools, should consider how they can work collaboratively with parents so that their insight can help shape services and ways of working.

5.2 There needs to be good signposting and referral routes to peer support, but also investment in organisations who can provide peer support, advice and information.

Experiences of adults with a learning disability

1. Support packages should be reviewed in light of the additional support people need to regain confidence going out after the pandemic. Enough 1:1 hours to allow people to go out should be a central part of support packages to support people’s mental wellbeing.
2. Health providers should review waiting areas and create a ‘quiet’ area if space allows.
3. Commissioners across different services should produce clear, accessible information for people with a learning disability to understand what health and social care services are available, how they work, and how to access them. This could take the form of an Easy Read booklet, co-produced with adults with a learning disability and voluntary sector groups.
4. In case of any further Covid-19 changes, ensure that information about services and changing regulations is readily available in Easy Read format, especially where this has not been provided at a national level.

5. Health related workshops should be commissioned/delivered to help people with a learning disability to explore health and wellbeing topics such as cooking, healthy eating, physical exercise, and mental health, in order to support their independence and wellbeing.
6. Mental health commissioners should explore the possibility of a service (or team within a service) who specialise in supporting people with a learning disability with their mental health.
7. When commissioning, reviewing, or inspecting services for disabled people, the views of disabled people (including those with learning disabilities) should be proactively sought and involved in decision-making. When disabled people raise concerns about service providers, these should be thoroughly reviewed.
8. To increase the uptake of Annual Health Checks:
    - 8.1 GP practices should proactively invite all people eligible for an annual health check each year, and offer reasonable adjustments where necessary (e.g. time of appointment, who they can bring with them, information provision).
    - 8.2 Community based health professionals and social workers should encourage and support patients with a learning disability to attend their Annual Health Checks.
9. To increase awareness of use of Hospital Passports:
    - 9.1 Deliver training to raise awareness of their importance amongst hospital staff, and explore barriers to staff using the passports that could be amended.
    - 9.2 Hospitals systems should flag that a patient is on the Learning Disability Register, reminding hospital staff to ask about Hospital Passports.
    - 9.3 Develop a monitoring mechanism to check whether hospital staff are looking at hospital passports during an inpatient stay.
    - 9.4 Community based health professionals and social workers should provide information to individuals with a learning disability and their families/carers to help them understand the benefit of a hospital passport, and support them to fill one in/signpost them to voluntary sector organisations who can support them.

Children, young people and families in Pitsmoor, Burngreave and Fir Vale

1. Statutory organisations should use targeted and culturally-competent ways to engage with Sheffield’s diverse communities. They should recognise where communities have a lack of trust in formal services/professionals and develop commissioning plans which take account of this, shifting more resource to ensure that trusted community-based services are able to meet the needs of communities. They could learn from existing community sector organisations which have built strong and trusted relationships within their local areas.

2. Encourage and facilitate opportunities for young people to support each other where appropriate, for example through peer mentoring.
3. Activities and training should be organised according to the specific areas of interest of young people and parents in the community, especially where they could improve health and wellbeing. These should be delivered in a culturally-competent way, for example by connecting and working with organisations that the community have trust in (such as mosques or other faith organisations).

People living with Dementia and their families/ carers

1. Establish clearer procedures around offering early support to families following a dementia diagnosis, with clear communication channels.
2. Increase staff capacity for Dementia Specialists throughout the Health and Social Care system. Where they exist currently in the system, what they do and how they can help should be more widely communicated.
3. New services/teams could be commissioned to address the following gaps in support:
    - A clearing house system/one stop shop/centralised dementia centre to offer practical support to families living with a person who has dementia.
    - A Sheffield Dementia Information Hub to fit with existing dementia support services (for a good example of this model, see the Dementia Services Development Centre at Stirling University).
    - A volunteer led befriending service to enable people living with dementia to have a better quality of life.
4. Ensure clear standards that all support workers employed with Adult Social Care should be able to meet if they are employed to deliver personal care.
5. Health and social care leadership teams should commit to making Sheffield a dementia-friendly city.
6. Create a multi-agency discussion group with the aim of seeking solutions that are Specific, Measurable, Achievable, Realistic and time-bound (S.M.A.R.T.).

People accessing maternity services

1. In case of further Covid-19 changes, provide clear and unambiguous pandemic restriction guidance.
2. Increase the postnatal support offer, with clear guidance and support for breastfeeding, physical recovery from birth, mental wellbeing of new parents, and questions around the health of the baby.
3. Ensure that signs of premature labour are checked for and that those that are pregnant are aware of the symptoms and know what to look for.

4. Offer increased support and care given to first time pregnant people.
5. Ensure that no one is left alone whilst in labour.
6. Work to understand the impact of Covid - supporting staff to understand and respond sensitively where people’s experiences have been impacted by Covid-19 restrictions and any ongoing effects this might have on them and their support needs.
7. Ensure that people in labour are given adequate pain relief – especially in light of accounts that Black and Asian women are less likely to have their requests taken seriously.
8. Health services should work more closely with community groups who may offer additional support for pregnant people and their families during a culturally significant time.
9. Ensure pregnant people have increased continuity of care. Seeing the same people throughout their care can lead to more positive birth experiences, increased trust and more open communication. This is especially important for pregnant people for whom there is a language or cultural barrier that may prevent them from receiving proper care.

Appendix

Each #SpeakUp project resulted in an individual report, which you can find the link to below. We have also included a link to each organisation’s website (if they have one) where you can find out more about them. We would encourage you to read relevant reports in full and consider the findings and recommendations that each one presents.

SACMHA Health & Social Care	> Report > Website
ACCT (Asperger’s Children & Carers Together)	> Report > Website
Autism Hope	> Report > Website
Luv2MeetU	> Report > Website
Burton Street Foundation	> Report > Website
Sheffield Voices	> Report > Website
Saalik Youth Project	> Report
Pitsmoor Adventure Playground	> Report > Website
Burngreave Messenger	> Report > Website
South East Sheffield Community Dementia Advice Service	> Report
JCI Sheffield	> Report > Website
Sheffield Maternity Co-operative	> Report & Zine > Website

Reading this as a paper copy? Reports can be found by visiting our website (www.healthwatchsheffield.co.uk/speakup-small-grants-scheme). You can also contact us if you’d like us to send you paper copies.

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