**Your Health, Your Voice, Your Life**

**A report about Self Advocacy and Health in the South West of England**

This report has been produced by Inclusion Gloucestershire. We are an all age, all disability, user led organisation based in Gloucestershire.

***Introduction***

The ‘Your Health, Your Voice, Your Life’ project was commissioned by NHS England. The project has involved 3 key staff members: Sammy Roberts is a person with lived experience of autism and has worked within user led organisations for many years – she has experience of working on a wide range of user led projects which have developed her expertise. Rosie Mockford is a registered learning disabilities nurse and also has lived experience – she has family members who have autism and learning disabilities. Vicci Livingstone-Thompson is the Chief Executive Officer of Inclusion Gloucestershire and has overseen the project. Vicci has a background in project management in the charity sector and like Sammy, she is an Expert by Experience.

The project began in January 2020. At this stage, the remit for the project was to engage with other user led organisations and individuals who have a learning disability and/or autism who live in the South West of England. The intention was to hold two events across the South West with a view to bringing people together to hear people’s views and to begin building a strong user led health network which would enable NHS England to share health messages. We were to bring together user led organisations and individuals so that anyone with a learning disability and/or autism would be able to have their views represented and voices heard about health issues.

The first 2 months of the project involved work to begin organising these events, in an inclusive and accessible way. There were a number of ways we had considered to make these events suitable and appealing for as many people as possible. This project plan was then amended due to the global Covid-19 pandemic and further details follow in the next section.

***What we have done***

When the Covid-19 national lockdown began, we reassessed how the project might be able to meaningfully continue since we would not be able to hold face-to-face events. Alongside NHS England, we agreed that we would still be able to engage with people in a meaningful way. Producing a questionnaire enabled us to start our work from the ground up, asking people what they want and need in a user led health network. We hope to respond to this in the next phase of the project.

We had already begun an in-depth research phase of the project which had enabled us to develop an understanding of what user led organisations exist in the South West. It gave us some information about the existence and successes of other user led organisations, as well as contacts for the project. Our research also focussed on **building a database** of other organisations which might be in contact with people who have learning disabilities or autism and/or their families. We **sent out the questionnaire to over 200 contacts** that we made, which covered service providers including sport and leisure clubs and activity providers, support providers and carers organisations. We were also able to talk to our existing contacts to ensure the survey got sent more widely, these included other user led organisations, contacts within health across the South West and local contacts from across relevant sectors.

It was agreed we would develop an **easy read survey** as well as an **online survey** through the ‘SurveyMonkey’ platform. We worked with NHS England to develop the questions.

At the initial planning stages of the project, we had already discussed how we could reach out to people in new or innovative ways so that we were as inclusive as possible. At initial stages we wanted to be able to engage with people online – e.g. through video conferencing. By conducting the research differently, through questionnaires, we have developed an understanding that some people – especially those who are autistic – prefer to have information prior to being expected to engage and we have also had feedback that some autistic people enjoy being able to write their thoughts down rather than engage in more ‘traditional’ ways such as face to face dialogue. We are aware that this, though, does not necessarily meet the needs of some people with learning disabilities although it may be right for others. Therefore, we know that **there isn’t just one approach that will suit all people.**

This project has aimed to **challenge barriers** such as the perception that statutory bodies such as the NHS doesn’t always listen; rather, people say that currently they can feel misunderstood and receive information about their health, which doesn’t always meet their needs. We are aware that people with disabilities often don’t feel heard or listened to so have been careful in explaining that we have NHS support and funding with our project to challenge this and begin to change these views. Our experience is that the NHS is committed to supporting and developing a truly user led health related self-advocacy network.



The project name “Your Health, Your Voice, Your Life” and the logo were chosen after much consideration about the impact this could have on people we hoped might engage with the project. Another consideration related to knowledge that some people who are autistic or who have a learning disability feel more comfortable when they know who they are speaking to. Therefore, we ensured to include information about the people working on the project in the easy read information in the hope it would support people to feel comfortable talking to us about the project.

We spent a lot of time considering the most appropriate language to use. For example, around a person with autism/autistic person. We had many debates around the people first /social inclusion model of disability and the overall outcome is that we felt people should be able to choose the ‘label’ or terms we use to refer to them. Our intention is to foster equality and equanimity in all our work and to always learn and strive for better. We have used both terms as we have found that people respond differently to each.

This **survey was developed by the end of May 2020 and sent out to over 230 organisations.** Individuals have also been **contacted individually** – for example members of the Inclusion Gloucestershire user led hub. The survey has also been shared via various **social media** channels such as ‘People First The Movement’, and various **learning disability nursing forums** that one of the project team is a member of. It has also been shared on social media by people outside the disability ‘world’ in the hope it will reach a more diverse audience. We ensured we targeted all the user led organisations in the South West which we were aware of through our research. We aim to build strong links with all the user led organisations that we have found.

Towards the latter stages of the initial project phase (mid July 2020), we were invited to attend and present at an LD England self-advocacy sharing session for self-advocacy organisations. Two other organisations from the South West attended. This enabled us to link with other organisations, both locally and nationally. We engaged with people who had not engaged with the questionnaire. We were able to **learn from health projects which have been successful** in Dorset and establish connections with multiple people and organisations. We were able to debate the challenges we’ve found with engaging with people who may have profound and multiple learning disabilities or not be able to engage with a questionnaire due to their disability. We were also able to discuss our limitations in terms of engaging with black and minority ethnic groups too. We have begun to establish links whereby we hope to collaborate in order to learn how to become even more inclusive than we currently are and become a strong voice for all people with autism and/or learning disabilities.

***What we found***

Initially we were just asked to engage with self-advocacy organisations. However, at the early stages of this research stage we discovered that **there were fewer user led organisations in existence than we expected and fewer than our experience tells us previously existed.**

Sammy Roberts attended the national self-advocacy conference hosted by LD England which helped us to understand the national picture better. Some areas of the country have more thriving and joined up self-advocacy whereas others, such as the South West, have more **fragmented services** which this project aims to address.

Our research showed us that **there has been a more active user led/self-advocacy community nationally, including the South West historically**. 10 years ago, through the national and south west regional forums, there was a more vibrant and thriving self-advocacy movement across the country. In the South West the group used café style workshops, meetings around pertinent issues to feed into the national forum and link in with central government.

According to the National Forum website, “The Department of Health funding to the regional forums ended on the 31st March 2017” but some forums are continuing to meet. We contacted the hosts of the South West forum, but we did not receive a response. We are aware that user led groups are more connected in the north than the south of the country. We also recognise that this project has coincided with an unprecedented global pandemic and therefore the capacity of organisations to engage and respond may have reduced. We will however, endeavour to link up as much as possible in any later phases of this project.

We found that user led organisations are now sometimes in the form of **much smaller organisations that might not be linked in with others**, and who are not centrally funded. Some user led organisations do receive local government and NHS funding as well as charity funding. We know there are lots of much smaller organisations trying to make a difference, often doing crucial work, but sometimes in isolation. Our experience shows that **together we are stronger**.

**Findings from Questionnaire:**

**110 people engaged with our online survey**. We had **8 easy read survey responses** returned. The graphs and images below represent all the responses we have received from both surveys. Responses are quoted as written by respondents. Appendix i) contains numerical data of responses given for each question. We feel that in many cases information on questions *not* answered by respondents might be informative to us too. There exists some commentary on the responses received under each question below.

Question 1:

Comment:

Although **some people are already members of User Led Organisations, most people who responded to our survey said “no” or variations of it**. Of those who were already part of a group, they were mostly from either Inclusion Gloucestershire or from Autism groups. There was less representation from other learning disability self-advocacy organisations.

Some people don’t know what a User Led Organisation is, which leads us to believe some work (perhaps nationally) could be useful in helping the voice of people with lived experience grow. This may fall outside of the remit of the current project but is nonetheless worthwhile knowledge to have gained.

Question 2:

|  |
| --- |
| ‘Other’ responses given: |
| 1. It would help me want to be part of a group if it was properly organised and run with clear instructions on what to expect
 |
| 1. I think an inclusive group for young people with a wide range of additional needs would be really beneficial as we all have shared experiences
 |
| 1. Groups should be for everyone with a chronic condition whatever it may be
 |
| 1. Groups should be for all learning disability and physical disability mental health
 |
| 1. I want a group for Family Carers
 |

Comment:

The responses to this question were rich, showing us that:

* There is some appetite for groups that are inclusive to everyone with a chronic condition.
* There is demand for a group for family carers.
* Any group run must be accessible for people with autism – clear, organised and with opportunity to prepare in advance.
* Some people who responded do not want to be part of a user led group, although most do.
* Some barriers to joining are: not knowing how to find a group, being worried about the cost to attend
* There is a clear demand for groups just for people with autism, and just for people with learning disabilities. Some people also want groups that are inclusive to all.
* People want to be able to access local groups.
* Some people want to be able to join in remotely.
* Although some people want to have fun, the main motivations to want to join a user led group are: to be listened to and to improve things.

Question 3:

‘Other’ responses given:

1. Filling in for pws [presumed to mean ‘person we support’]
2. Friendship & support
3. To help People With mental health Anxiety stress low self esteem lack confidence To feel good be happy
4. My sons level of understanding means that this survey is meaningless to him -even the easy read - he would engage with fun activities to do with health if his communication and sensory needs were understood. He would need lots of different activities repeating the same theme - his voice is important but there must by many people like my son who remain unheard.
5. I would need more information about it to know if I'd want to join in the first place. It would depend how things were run, who was running.
6. Because I enjoy hearing about other people's experiences
7. I have a public health degree and wish to use this to help others.
8. I think i'd learn more than anything else - i want to hear whatever they talk about. I want to help other people too.

Comment:

This question differed from question two because it focuses on if people specifically wanted to be part of a user led **health** group. Again, **some people did not want to be part of a group of this nature, however most did.**

Of those who did, we learned:

* People want to **be listened to** and **learn.**
* People want to share both positive and negative experiences of healthcare. Slightly more people said their experiences have been negative.
* The ‘other comment’ section enabled people to explain what might help them participate in a user led health group, and also showed that there is knowledge and passion which others are keen to share. People say hearing about other peoples’ experiences is powerful.

Question 4:

**What do you want people in charge of health (the NHS) to know about helping people be healthy and well?**

|  |
| --- |
| 1. Advice from Doctors
 |
| 1. Yes that would be great
 |
| 1. Doctors are helpful
 |
| 1. i want people in the NHS to understand people have Learning disabilities. I didn't want to go to hospital because I took too many tablets, but I didn't want to go to the hospital. They rang the doctor and asked him and he said I didn't have to go.
 |
| 1. Occupational Therapy; nutrition
 |
| 1. to explain things in a way I understand
 |
| 1. People with Autism should not be turned away from mental health services because we "don't meet the criteria" or whatever.
 |
| 1. Treat as individuals and never assume they don't understand or cannot speak for themselves. To given same access/priority to care/treatment as everyone else
 |
| 1. Young people with autism deserve to have their MH difficulties addressed properly through CAMHS and not dismissed as ‘part of autism’
 |
| 1. Don’t know
 |
| 1. It’s not always diet and exercise but mindfulness too
 |
| 1. Clear consistent advice
 |
| 1. To listen to them and tailor support to the individual rather than dismissed or put it into a group criteria that does a one size fits all ethos when we aren’t all the same.
 |
| 1. That we are real people with real feelings and needs not statistics
 |
| 1. Listen to people with lived experience before making decisions
 |
| 1. Mental health Can go up And down And people Feel alone And find it hard to cope People should not have to reach crisis point Before social worker or community nurse happen As it harder for learning disability disabled people To handle cope with hard feelings moods
 |
| 1. Listen to individuals and their families to learn the best way to support us
 |
| 1. More liaison nurses - in gp surgery, dentist etc more autism training to help people understand communication and sensory needs and how they impact on health
 |
| 1. People with learning disabilities, autism, behavioural issues may find it difficult to understand what being healthy and well is
 |
| 1. If I'm part of a group I always like to feel I'm giving as well as receiving. In my experience I think health services in Gloucestershire aren't as good as other areas for people with disabilities. Their attitude can be wrong...a health professional in bristol, oxford and gloucester can all tell me the same thing but sometimes people in gloucester don't have the understanding that others too. People locally can make me feel not good or like people don't really understand me.
 |
| 1. It is important to be healthy
 |
| 1. Knowledge of diagnosis of autism in the transgender community is severely lacking
 |
| 1. listen to them, talk at there level of understanding, give them time to process, be realistic,
 |
| 1. The secret to mental health doesn't solely lie in rational thinking. In a lot of cases our limbic system has decided long before we've consciously observed triggering stimuli. Seeing all suffering as ideological in nature ignores the emotional side that can't simply be reigned in with reason.
 |
| 1. listen to us
 |
| 1. I want them to understand people with a learning disability more.
 |
| 1. The current system is reactionary - there is nothing until you’ve passed crisis point.
 |

Comment:

We feel people’s views speak for themselves. Our hope is that NHS England will continue to support our endeavours to be responsive in those areas we can take positive action in. Some (such as more liaison nurses) are beyond our realm of influence.

Question 5:

**What health issues are important to you?**

|  |
| --- |
| 1. Dentist and easy read
 |
| 1. Healthy eating & keeping fit and well
 |
| 1. Dentist
 |
| 1. Diabetes, Going to hospital, Annual Health Checks
 |
| 1. Poor exercise, over eating, limiting diets
 |
| 1. my annual health check is important to me. having easy read information.
 |
| 1. Mental health and IBS - both neglected by most NHS professionals and services.
 |
| 1. All the above. To be treated like everyone else
 |
| 1. Assume competence. However, give time, space and ask questions to ensure understanding
 |
| 1. Asperger’s syndrome awareness for the people that have the condition to help in waiting areas so they don’t overload with noise ,lighting or being in busy / crowded areas. A place separate for them to be waiting
 |
| 1. Mental health. Related issues with autism
 |
| 1. To have the ability to get simple advice for basic home treatable illnesses without having to see a doctor or going through complicated phone calls or sites
 |
| 1. Health passports. More understanding of hidden disabilities. Things like disability benefits, bus passes/blue badges more available and easier to get for those with hidden disabilities.
 |
| 1. Support, a doctor etc bring trained in autism for starters would help
 |
| 1. Regular monitoring of my multiple chronic conditions
 |
| 1. Mental health Physical therapy Sensory Mindfulness Play laugh Learn smile
 |
| 1. All health issues need to be documented and how to support each person in their own way
 |
| 1. Easy read is generally too difficult for him to understand -activities and peer led groups talking about the subjects could be helpful
 |
| 1. Easy read information to be widely available. Involving and listening to family and/or carers of LD etc in their healthcare
 |
| 1. Being able to make a doctors appointment without it being stressful and without the receptionist asking unreasonable questions or respecting the fact you don't want to go into private business with a receptionist. Respecting the fact not everyone understands automated voice stuff and just needs to speak to somebody. Seeing more of the same regular GP rather than lots of different ones. Awareness and understanding - people knowing that you might have a hidden disability like specific learning difficiulty or learning disability. Sometimes people don't understand you which can lead to tensions rising - if they knew better how to support people like me it would stop horrible situations happening. Learning about health passports - I have complex needs that include spLDifficulties but not a learning disability. I benefit from extra help but don't know about health passports and don't get invited for annual health checks. Staff can be too overworked, pressured or tired - it can feel that they're taking it out on patients sometimes, it really doesn't help me feel good about seeing them.
 |
| 1. Annual health checks
 |
| 1. Dental health, keeping on top of my medication, eating well, sleeping well, managing anxiety, sleeping well
 |
| 1. being listern to and taking it on board
 |
| 1. Autism
 |
| 1. Obesity. I'm currently obese and so that is important for me. I know diet is important and my NHS dietrician has been helpful in conventional dietary guidance. Though there was little to really address the dicipline needed to stick to a healthy diet and the stress I seem to go through when trying to stick to it. I also see a lack of education on exercise. I have misophonia and can't go to gyms so I have to do my education and exercise as home. It's just so hard to try to navigate what is good and what is bad advice. Most of YouTube is full of meathead gymbros who care more about visible abdominal muscles than actual health. I would like more accessable information about home based exercise for all major kinds of exercise. Something that almost anyone can use to talor to themselves. "Mental" health (I personally don't like Cartesian dualism). CBT has too much of a monopoly on mental health. Even when it doesn't the core ideology still does. It is assumes that all suffering is ideological in nature, which is just not true. When I see a spider, the signal travels from the eyes; to the 2nd cranial nerve; to the midbrain (unconscious); to the limbic system (still unconscious) which is then given an emotional encoding; then to the temporal lobes (first sign of conscious awareness) which combines all sensory data into conscious awareness. So even before I consciously see the spider, my brain has already recognised this as a threat. So why is it considered imortant to treat such things as "core beliefs"? The core belief model seems a standard part of psychotherapy, yet no evidence seems to be for it. I even had my therapist lie to me as a part of using this model. Psychotherapy needs a revolution and realise that not all emotions are caused by beliefs. Just because the behavioural model of cause and effect didn't work for everyone, doesn't mean that the only thing in our heads that may resist healing (or trigger us) is our beliefs. This is stupid and dehumanising as it limits us to mere belief systems when we're much more than that. It also can harm us.
 |
| 1. Having someone come with me to help if I don't understand the question. People don't always know that liaison nurses are there - I didn't and others might not know they're there to help. I know health is important and want to learn more - you can learn from other people.
 |
| 1. Health passports and annual health checks. But also whole family mental health.
 |

Comment:

Again, the answers here speak for themselves. Many important health related issues are raised. Some themes coming through are: dentist, mental health & emotional wellbeing, reasonable adjustments and issues relating to obesity.

Question 6:

Comment:

Most people did not respond to this question – as the questionnaire continues more people gradually ‘skipped’ questions. We feel this shows that around 5 questions would be a sensible level to ask in future, if we were to consult again.

Of those who did respond, it showed **funding for user led groups comes from a range of sources.**

Question 7:

|  |
| --- |
| ‘Other’ responses given: |
| 1. Help overall
 |
| 1. I think all the options might work or might not. They're all a risk and a gamble!
 |
| 1. I had a small grant from my University and need help with the accounts, also with securing volunteers to help run the groups. We have no regular funding
 |
| 1. Having people come and give talks about different things and it would be good if we were able to pay for this.
 |

Comment:

Most people felt **more money and more members** would support their user led organisations to get stronger. Others felt help to self-organise, and joining up with other groups would also help. A few felt more staff might help and others did not know what might help.

Question 8:

**Please tell us if there is anything else that would help you join a user led organisation, or help your group grow and get stronger?**

|  |
| --- |
| 1. More people could come to the group
 |
| 1. People listening
 |
| 1. Games Walking and a ladies group
 |
| 1. I don't know what a user led group is
 |
| 1. maybe just wanting to meet people from other groups. I like to meet people from other groups.
 |
| 1. don't know
 |
| 1. I don't want to be part of a group
 |
| 1. Nothing specific.
 |
| 1. Availability, suitability in terms of age etc
 |
| 1. Convenient
 |
| 1. Awareness of them being available.
 |
| 1. Help getting there and overcoming anxiety of actually starting to attend
 |
| 1. Knowing that other members understand
 |
| 1. Transport
 |
| 1. Sensible times
 |
| 1. Just keep up the good work everyone! Lockdown restrictions ending! And for this all to last and expand, we need to grow. Also offer more guarantees for income for projects - so that there is less uncertainty for staff and insecurity in their roles.
 |
| 1. To discuss my needs
 |
| 1. Having home help with me also the traffic light cards whether it be for social or more formal meetings.
 |
| 1. Some guarantee that it will solve my problems.
 |

Comment:

The responses here build on those provided in question 7. Again, they speak for themselves. Some suggestions for what might support the quality are helpful e.g. potential for games, walking group and ladies’ group. Others make it clear that meetings being convenient and accessible is imperative whilst others highlight again the impact anxiety can have on wanting to join in with such groups. We would want to carefully consider how to address these potential barriers whilst providing what people say would benefit them.

Question 9:

**What else would help you speak up about health?**

|  |
| --- |
| 1. A group to talk about things that help people
 |
| 1. information From Doctors
 |
| 1. Tips on the right foods to eat
 |
| 1. more information
 |
| 1. My support worker.
 |
| 1. Confidence
 |
| 1. nurses are nice.
 |
| 1. Nothing specific.
 |
| 1. Transport, access
 |
| 1. Feeling like I am genuinely being listened to (from my young person)
 |
| 1. Being listened too. Taken seriously
 |
| 1. More health workers asking to hear issues
 |
| 1. More people who understand hidden disabilities.
 |
| 1. Feeling that my voice matters
 |
| 1. I already do by volunteering for various health & disability organisations
 |
| 1. Doctor nurse Staff Social worker
 |
| 1. People who are willing to listen not just with their ears!
 |
| 1. Opportunity
 |
| 1. Just the feeling on the day - sometimes it depends what others say when you're in a group to feeling ok to speaking up. You need to feel comfortable in the group.
 |
| 1. Being part of a group speciffacly for that
 |
| 1. Due to my autism and cptsd I have difficulties accessing my memory so having questions in advance can help.
 |
| 1. I guess it depends on how accessable it is. This survey was good as I was able to get things of my chest without leaving my home or skyping anyone. I'm usually willing to talk about my problems with health, unless if I'm too stressed to go down that dark path of bringing up issues still yet to be solved.
 |
| 1. If I had prompts (someone there or it written in front of me) so I know what to say.
 |
| 1. A feeling like someone might actually help.
 |

Comment:

Again, these answers are powerful in themselves. We would seek to respond to some requests e.g. advance preparation time for participants, a genuine two-way dialogue with professionals, being listened to and understood and relevant learning.

Question 10:

**Is there anything else that would help you talk about health?**

|  |
| --- |
| 1. They put needles in me in hospital. They took my blood at 6am in the morning. I think they had to do that by law. I don't think you can refuse a blood test. I wasn't sure. They didn't explain to me about my broken ankle. People say when I go to the toilet a lot that might be to do with sugar getting rid of. I'm not sure.
 |
| 1. Engagement with health professionals
 |
| 1. no thank you
 |
| 1. Nothing specific.
 |
| 1. People to listen and treat us like everyone else
 |
| 1. Not dismissing my anxiety as ‘just part of autism’ and leaving it as something I have to tolerate, but something that I deserve specialist support in managing.
 |
| 1. It’s difficult to point to one thing.
 |
| 1. Offering adjustments like emails/written communication via WhatsApp/messenger instead of everything being done face to face or phone calls.
 |
| 1. Peer support/buddy
 |
| 1. I have too much to put here
 |
| 1. Transport
 |
| 1. Accessible formats and different processes for all
 |
| 1. Small groups. Knowledge of group before actually going.
 |
| 1. Giving longer appointment times
 |
| 1. Everybody being nice, respectful and understanding to each other. Maybe a few perks like biscuits/cakes to get me to engage with groups! Made to feel really welcome and wanted in a comfortable environment.
 |
| 1. Checking my weight etc
 |
| 1. Allowing me to bring my laptop, my comms cards, my support worker, asking specific closed questions.
 |
| 1. Being able to talk to others about it if you've had a problem. It would be good to talk in a group - we could help give a talk to them.
 |
| 1. Having the resource to actually help!
 |

Comment:

Again, these varied responses tell us a lot about how people can feel best supported to feel welcome in a health group. They also reinforce the appetite for such groups that exists.

Question 11:

**Is there anything else you want to tell us?**

|  |
| --- |
| 1. That I am a competent, intelligent young person if you take the time to communicate with me in my way.
 |
| 1. There are little services to help me and my age so just to talk will help
 |
| 1. Sometimes more awareness. You don't really know about user led groups or things that are happening. Unless a social worker or someone from inclusion tell you then you just don't know. You'd have thought with my history I'd have known it a lot sooner! I think we need to have more user led organisations or existing ones need to expand their capacity so more people can access them.
 |
| 1. I'm a wheelchair user and may interrupt by accident due to my autism. Please be patient with me
 |
| 1. I really hate CBT and stoicism.
 |
| 1. I don't mind if the group tells us what to talk about or if we suggest ideas of what we want to learn.
 |

Demographics:

The youngest respondent was 16; the oldest 68. We had males and females respond and representation across most counties. We did not receive responses from either Bath and North East Somerset or from Wiltshire, so would seek to increase focus in these areas – particularly with other user led organisations in these areas to begin. All but one person who responded was white British; the other person identifies as “Mixed race pale complexion”. 7 people who responded are family carers, 2 are paid supporters and whilst some people did not want to answer demographics questions about diagnosis labels, those who did were fairly equally split between people with autism, people with a learning disability and both. We also had respondents who said they didn’t feel they fit into any categories but would benefit.

***What will it take to get us were we need to be*?**

Our work producing the questionnaire and analysing the resulting data has shown us that there is a **strong appetite for health related groups which are run in a user led way.** We have learned that for some, engaging through a questionnaire rather than face-to-face events works best. For others, surveys do not feel accessible – in part the very low return rate of easy read surveys exemplifies this. The global pandemic may also have limited the reach of the survey. Anecdotal evidence gathered via verbal conversations through the course of this initial research project have shown us that many people cannot complete surveys themselves. Family members and advocates told us that the survey was confusing as they were unsure if they were completing for themselves or for people they support. We found many people skipped questions too, which we understand as meaning the survey was too long. This is all very useful learning. The project team have discussed the potential that having a learning disability nurse within the team offers; they could coordinate responsive health related groups which could be run by self-advocates & perhaps following a model used by another user led group in the South West. We would seek to collaborate with others.

**Recommendations:**

1. Informative, interactive, safe and fully accessible user led health groups and resources are needed for:
	1. Autistic people
	2. People with a learning disability
	3. People with a learning disability and autism
	4. People who support people with a learning disability and/or autism (e.g. family members)
	5. People with a chronic health condition (an inclusive group)

*These may be able to take the form of women’s and men’s groups where appropriate – this has been a successful user led model elsewhere in the southwest. There could be additional novel work e.g. accessing reasonable adjustments, what to expect when going to various health professionals, work around dental care or obesity related issues.*

1. Effectively respond to people’s request to learn about more about health and have ownership of their own health needs – equip people to provide information to people around them as they choose e.g. supporters, family members, health professionals.
2. Facilitate a two-way dialogue with health professionals - we aim to be able to support a two-way learning process. As well as receive education we hope to support them to learn about reasonable adjustments and communication needs.
3. Explore what more can be done to engage with and support people who services typically struggle to engage with e.g. those with more complex Learning Disabilities, people from Black and Minority Ethnic Communities, Transgender.
4. Explore one theme at a time, providing opportunities for repetition for those who would benefit.
5. Provide accessible forums and networks, ensuring information is available to others in a range of appropriate ways e.g. online conferencing/video, youtube/website, email, written information and face to face.
6. Maintain, develop and strengthen communication with individuals and organisations in the region who have already engaged with the “Your Health, Your Voice, Your Life” project.
7. Continue ‘outreach’ work to link with other user led organisations in the South West.
8. Develop a strong user led health network across the whole South West region.
9. Establish further links to grow the South West Forum so that we can link with this.
10. Maintain close links with LD England to ensure that any resources and learning can be shared. Collaboration, synergy and working in partnership are crucial.

**Conclusion**

We feel that there is a growing appetite for self-advocacy again. This is extremely positive, and we know it is imperative to ensure that the movement grows and strengthens. Inclusion Gloucestershire have been able to create a synergy with the work LD England are doing to develop stronger links with the national user led movement as well as that in the South West. NHS England have funded this health project work and we have an ongoing commitment from and to them to build a genuinely inclusive, effective, and responsive user led health network across the South West. We hope to link in with many other people and organisations in the area to learn and share experiences to ensure it is strong, enduring and sustainable. We hope to be able to respond to what people have told us would help, by offering effective and responsive health groups which could feed into a regional health network (whilst maintaining national links), in order to build the trust people have in the NHS and in user led organisations and be truly responsive to what people say will help with the ultimate goal of improving health outcomes and reducing health inequalities.

Appendix i)

Number of responses given to each survey question:

|  |
| --- |
| Question 1: |
| Yes | No | No but I would like to be | I don't know what a user led group is | I used to be | No Response |
| 20 | 33 | 4 | 12 | 2 | 50 |

|  |
| --- |
| Question 2: |
| Help finding or joining one | Help with money  | Being listened to | Knowing it will make things better for me | Knowing it will make things better for other people | I want to have fun there | I want a group just for Autistic people | I want a group just for people with Learning Disabilities |
| 13 | 6 | 18 | 16 | 21 | 12 | 18 | 10 |
| I want a group for everyone with Learning Disabilities and Autism! | I want meetings near me | I want to be able to join in without being there (e.g. through videos, phone, internet, questionnaires etc) | I don't want to be part of a user led group | I don't know  | I am already a member of a user led group | Other (see table below)  | No response |
| 10 | 17 | 12 | 9 | 2 | 15 | 5 | 51 |

|  |
| --- |
| Question 3: |
| I think I would enjoy it | I have things I want to say | I have things I want to learn | My experience of healthcare wasn't good | My experience of healthcare has been great | I want people with lived experience to be listened to | I don't want to be part of a health group | Other:  |
| 17 | 16 | 24 | 12 | 9 | 27 | 10 | 8 |

Questions 4 and 5 are open ended – see full text responses in report.

|  |
| --- |
| Question 6 |
| It gets government funding – from local council or the NHS. | It gets charity funding | It gets money another way | I don't know where the money comes from | I am not in a user led group | No response |
| 7 | 7 | 6 | 6 | 11 | 85 |

|  |
| --- |
| Question 7: |
| More money | More staff | Help to self organise | More members in the group | Joining up with other groups | I don't know | I'm not in a user led group | Other |
| 13 | 4 | 7 | 10 | 7 | 6 | 9 | 4 |