



Your Voice Counts: Learning Disabilities and/or Autism

Phase One Report - September-December 2016

The project

'Your Voice Counts' is a project commissioned by North East Hampshire and Farnham Clinical Commissioning Group (CCG). The aim is to gather the public's experiences of using mental health services and look at the support that they receive and how it can be improved. The project achieves the CCG's objectives to involve mental health service users, carers, providers and voluntary and community organisations in providing feedback on services and developing the CCG, Local Authority and partners commissioning intentions.

The Wellbeing Implementation Network, run by Hampshire County Council, was set up to provide a forum for service users and stakeholders to contribute to local service design and delivery and learn about future service plans. In recent years, the number of service users and carers attending the quarterly meetings has been reducing and North East Hampshire and Farnham CCG are keen to reinvigorate an approach putting service users and carers at the centre.

The "Your Voice Counts" project is focusing on four groups that access mental health services;

- Young people accessing CAMHS or that are/have transitioned to adult services
- People with dementia
- Learning disabilities and/or autism
- Adults with general mental health issues

The project consists of a number of different approaches including public engagement, focus groups, surveys and follow up conversations; all aimed at increasing knowledge of the needs of the local population and establishing a clear and effective way of ensuring that the voices of service users, carers and the public can genuinely influence commissioning decisions, and ultimately, inform service improvement for local people.



The final reports on engagement with the public will be submitted to the CCG at four periods of the year. The initial focus group work shows that the public are involved right from the start - helping to shape future engagement work as well as sharing their experiences, ideas and recommendations about services. We will ensure that feedback is anonymous where necessary.

These reports and their recommendations will also be shared with anyone who has taken part in the engagement. The final report, referring to all four categories and mental health services, is due at the end of September 2017.

Executive Summary

The Healthwatch Hampshire team have carried out focus groups, conversations, and engagement events in five different towns throughout North East Hampshire and Farnham; Fleet, Yateley, Farnborough, Aldershot and Farnham. These events, led by Fiona Biggs, were attended by individuals, parents, carers, professionals and volunteers from across the health and social care sector; Community Ambassadors also attended to support the event.



Our key findings included:

- The referral process- waiting for the referral to mental health services to be processed when at crisis point, there is a need to look at options around preventive services and how this would be more sustainable if they are put in place. Some even suggested that if this is done, they would not be at crisis point.
- Resources- Alternative contact or hub of information rather than through their GP, taking the pressure off GPs as they are the first point of contact however GPs felt that they are not confident in signposting to an appropriate Learning Disability (LD) service or unknown to them
- Resources- to be made available in easy read or alternative formats
- Parents and carers are a big resource that is under-utilised by GPs and/or by other services
- Parents and carers are not supported enough for their mental health and wellbeing
- Lack of local services for mental health in their area- some are aware of the Wellbeing Centre in Aldershot and feel scared to travel to get the support they need when they are in crisis
- Nearly half of the GPs that we spoke to felt that they were not confident to do a Mental Capacity assessment on their patients with a learning disability

Background: Learning Disabilities and/or Autism

The theme for the first stage of the project is "Your Voice Counts: Learning Disabilities and/or Autism". The main focus of the engagement, based on CCG intentions and feedback gathered by Healthwatch from across the county and locally, was access to GP services, hospitals, mental health services and availability of local support services.

People with a learning disability are more likely than the general population to have a mental health condition (*Department for Communities and Local Government, 2008*)

This part of the project was looking to gather feedback from people with a learning disability and/or autism and their carers, relatives and professionals that work with them, about the mental health of service users and whether they were aware of what services are available and their experiences of these services, if they have accessed them. The questions we asked have been created around the themes that were developed and coproduced, through speaking to small focus groups in each locality from November 2016, alongside individual conversations. This part of the project was carried out in the Hart and Rushmoor locality and helped us to get a better understanding of each town's needs and services, as



well as giving local people further opportunities to talk to us. At this stage we asked general questions such as;

- "What mental health services did you access to support your needs? And what was your experience like?"
- "Do you know where to go or who to ask if you need support around your mental health?"
- "Did your GP offer alternative support or information?"

Methodology: Focus Group (Aldershot Wellbeing Centre)

This 1-to-1 engagement took place alongside a social club in one of the halls at St Joseph's Church in Aldershot. The session was attended by 15 adults between the ages of 32 and 65 and 5 people gave detailed feedback and shared their experiences. mcch's aim is to enable individuals to live as independently as possible and support them to reach their potential. Their staff are passionate about enabling people to lead fulfilling lives and achieve their aspirations. They are working in collaboration with the Wellbeing Centre in Aldershot. The group is reliant on information found via the Wellbeing Centre. All attendees have a learning disability, had or currently receive mental health support, and are welcomed into the group to socialise if they wish.

mcch aims to support service users to...

- Have choice and control
- Have respect and dignity
- Be independent, safe, healthy and well
- Be involvement and take part
- Have rights and responsibilities



Key issues raised during the session

When engaging with the group, there were issues that arose repeatedly and could therefore be further explored during future engagement work.

The group discussed seeing their GP and their emotions, not knowing about what support is available and having to go through the process of getting referred by their GPs to further support services, the lack of information when they have been discharged from the service, minimal guidance of how to get future support and being unclear about the support was available in their locality and GPs being supportive but not being aware of their mental health needs.

A breakdown of the issues discussed with each of the group that attended the session and spoke with the Healthwatch Engagement Officer and CAB Officer on a one-to-one basis are included below...

Case Study 1:

Male, Age 55

- Location: Camberley
- Travels to Aldershot to socialise
- Epileptic, asthmatic, diabetic, arthritis, partially deaf
- Has a care worker 3 days a week at home

Please share your experiences of local mental health services.

"I go to my doctor about my diabetics, I feel like I can talk to them about anything. I get a care worker at home for 3 days and I enjoy it every time they come as they encourage me to get out. I have been doing drama for 12 years (at St Joseph's) and put on a show at

West End Centre every year. I have been coming to this group 25 years it works well for me."

What would you change if you wanted or needed something to keep you well?

"I think there should be more groups like this, Richmond (Fellowship) told me to come here as it will help me. It has and it's run by Suzanne. I want to go to other groups when this is not on but I don't know where to go. If there is no groups, I am sat at home in my chair and that's boring."

Case Study 2:

Female, Age 55

- Location: Aldershot
- GP surgery: Princes Gardens
- Has depression, mild anxiety, psychosis and an eating disorder

Record the difficulties that you have experienced when accessing mental health services locally.

"I was at Hollies community mental health team and this was nearly a year ago. I felt unsupported and they wouldn't offer me medication. I was discharged with little support. I got sent to the Priory and they are still looking after me through the NHS. I have very good GP support at Princes Gardens."



Case Study 3:

Male, Age 53

- Location: Aldershot
- Has depression, visually impaired and had a stroke in July 2016

Please share your experiences of local mental health services.

"The mental health team referred me to this group. I was in Aldershot Centre for Health and got told I'm depressed. I had a certificate from my doctor to say I've done my mental health course to help me get better. Last time I went to my doctor was last year. It's been a while as I cannot see and I got no one to take me. When I was told about me not being able to see, no one helped me with that. I didn't get support. I was in hospital April all the way to July because I had a stroke. They didn't understand my needs, I did not get anything, no one told me what happened and I kept asking to get someone to tell me what was going on and no one explained what happened."

What would make it easier for you?

"I want to do things everyday, I rather to do something than nothing at home. I only come to this group. I have been waiting for a wheelchair for 17 weeks through my doctor and I was told 16 days. They told me they can ring me but no one has. I want someone to take



me to my doctor to ask how long to wait. Nobody to give me a choice. I want something free to do too."

Case Study 4:

Female, Age 46

- Location: Blackwater

Please tell me about the time you see your doctor, anything good or bad happen? Do they help you?

"I have a good time with my doctor. I ask my brother for help."

(Project officer asked if she ever asked her doctor for help- "I didn't know I can ask my doctor for help. I ask my brother for help, I think I have enough help from him, he's my brother, he can help me.")

Case Study 5:

Female, Age 48

- Location: Farnborough
- Does not like taking medication
- Has anxiety attacks and depression

Record the difficulties that you have experienced when accessing mental health services locally.

"I come here and sometimes to Branches (Farnborough), the job centre told me to try it as I have moved and I felt lonely at home. I am worried about my future. I have seen 3 or 4 different doctors and I find it hard to talk to them as it is always a different doctor. I seen them every 4 weeks because of my tablets and I don't like taking them. They are easy to understand. They did not tell me about the groups or what other things happen in Farnborough, the job centre did that. I'm happy I am here as I like meeting people.

What would make it easier for you to access mental health services locally?

"I want to have the same doctor. I want the doctor to tell me about anyone who knows what things are happening in Farnborough. Branches has helped me with house stuff and I was suicidal and low. I wouldn't be good if they were not there and I am happy the job centre told me about them and here. I want more people to know about them, they are good. I have a friend in Yateley the same as me, I told her about here but it takes her two buses to get here so she doesn't come."

The following recommendations were made by the group for future engagement:

- The informal setting in the social group works well for this group because it allows them to approach us without feeling pressured. Setting up a focus group within this group means that they incur no travel costs and is accessible for any newcomers.
- There are MCCH staff with experience who can signpost to the appropriate support or disclose to Wellbeing Centre in case of a need for emotional support.
- Being able to discuss experiences in a confidential 1-to-1 way is really important because many of them have personal issues, medication and diagnosis' that they might not want to address in front of their peers but are happy to discuss when they understand that feedback is anonymised.

Focus Group: In Summary...

The main issue highlighted by this group was getting support to access information through their GP. Not necessarily the access point but the alternative ways of accessing those services, such as having an information hub where service users could make the decision about which services they would like to be referred via GP support. Some service users in

the group were showing frustration of not knowing what services are available and thought they cannot access this unless they have been referred by their GP. Other issues raised were around not consistently seeing the same GP, not seeing the GP at all and a lack of choice in what services are offered and available to them.

Methodology: Public Engagement Events

The engagement events were held in five localities. This approach was based on feedback from local groups about having the opportunity to access these events locally, without the concern of travelling a distance, or an impact on daily routine or activities.



We organised a series of activities using polls, playdoh, target boards, voting boards, cupcakes, filming and photography. This method was used to ensure the questions were broken down to make them more accessible in an informal setting, with fun interactive ways of communicating feedback and ideas.

"They are much more likely to be reliant on others for some aspects of daily living, such as communicating their needs." (DCLG, 2008b, p7)



North East Hampshire and Farnham CCG were interested in finding out specific feedback regarding GP services and how they deal with mental health issues. Feedback gathered by Healthwatch was then used to inform a training session for GPs and practice staff on the topic of mental health and learning disabilities.

The questions used throughout the activities were also tried and tested with two different community groups for people with learning disabilities and their carers, to ensure the use of language was simple enough to be understood.

Questions

- What would you like to ask your doctor?
- If you were the boss of all doctors in England, what would you make sure they do?
- Tell me about your last visit to your doctor?
- What is the good or bad thing about your doctor?
- Why is it important to be listened to?
- Do you see anyone from the community mental health team? Do they help you feel better?
- (Alternative question) Who helps you? Do they make you feel better?
- Do you get enough help to make you feel healthy?
- Do you get enough help to make you feel happy?
- When you are scared, where would you go?
- Appointments- tell us about them (How easy it is to get an appointment?)
- When was the last time you saw your doctor?
- Do you have any new ideas you would like to share with us to make health services and mental health services better for you?
- Is it easy or hard to understand your doctor?
- Do you feel involved in your care?
- Would I prefer to
 - See **any** doctor in my doctor surgery
 - See **my** own doctor in my doctor surgery
 - See **someone** else like a nurse, pharmacist or other healthcare professional in my doctor surgery.
- I would prefer to
 - Speak to a doctor or nurse on the **phone**
 - See a doctor or nurse **face to face** at my doctor's surgery
 - Talk **online** to a doctor or nurse from my doctor's surgery
- The most important to you to the least important to you
 - I want to get more information to help me and go to social groups
 - I want someone to help me quickly when I really need it
 - I want my doctor to understand my mental health issues (Feeling low, anxious or depressed)
 - I want to access to mental health services near to where I live
 - I want to be referred by someone else instead of through my doctor
- I do/do not have a health check every year
- My doctor understands/does not understand what I need
- Who do you ask for help when you feel low or sad?
- Do you look after yourself or does someone help you?
- Do you think your doctor knows enough about you to help you?
- Have you heard of Recovery College? If yes, was it good or bad and why?
- Have you used the Wellbeing Centre or Safe Haven in Aldershot?

Other conversations

The project also gives people the opportunity to tell us individually, in a comfortable environment, about their experiences of accessing local services. Comments gathered included:

"I don't want to live in a doctor's surgery" (Farnborough)

"I ask my family when I feel sad and low and they are always willing to give me support" (Farnborough)

"I like how if you go to my doctor with a mental health problem, she'll take care of the physical and the emotional side of things. She will always try to understand me no matter what the problem is, even if she has understanding of it herself - she'll always try." (Aldershot)

"I am forced to get in a situation I don't want to" (Farnham)

"I do feel involved in my care. I always keep well" (Farnborough)

"I don't feel involved in my care. I find a lot of decisions being made for me such as discharge - even if me and the people around me think that it's a bad idea, they'll still go ahead and do it anyway. They just don't listen to you, they think that they know what's best for you but only you know what's best for you." (Aldershot)

"Trying to calm me down in the waiting room did not help but was helpfully met"

"My daughter has a mental health diagnosis. She still has, but in February she was diagnosed with autism. They realised that her issues such as meltdowns were related to autism. Before they thought she had borderline personality disorder (BPD). The community consultant is fairly clear that her behaviours are autism related and my daughter agrees. The Inpatient consultant thinks it's BPD, I don't think he has much understanding of autism. This is making it very difficult to get help and make progress." (Farnborough)

Do you find it easy to talk to the professionals that you deal with?

"Yes and no. Sometimes they'll make it easy to understand for you or you might just understand anyway because you've been experiencing it. But other times, they just make it hard for you to understand because they use a lot of technical terms and they don't go on to actually explain what that means." (Aldershot)

"We need practices to be more LD friendly. GPs need time and skills to implement this. They need to listen to carers and their family members, treating them as equals." (Farnborough)



"Professionals should try and listen to their patients. Take them seriously, don't just discard anything that they say. Always listen to every point and try your best to understand even if you haven't been through it yourself." (Aldershot)

"Coping strategies given, before leaving an appointment- tools & techniques to use, if they don't know- print them" (Aldershot)

"Some options are not suitable for people with social anxiety" (Aldershot)

"Listen to the person who has autism- consistently follow the adjustments they are asking for where possible." (Farnborough)

"GPs to have the skills to reword questions to extract information. Address both carers' wellbeing needs, so they are supported by GP as well." (Farnborough)

"Don't ask leading questions, give enough time to answer. GP should give longer appointments for this." (Farnborough)

"GP should ask for feedback of the appointment to try and improve" (Farnborough)

"I waited a year for an operation but was told to go to Middlesex. I don't know where Middlesex is so I asked my son to drive me. They wanted me to go every month because of my hernia. I was told to lose weight but I have."

"When my daughter goes to her GP, I go with her. She cannot speak, but understands others. She can say a few words. When the GP talked to her about sleeping tablets, she doesn't understand at all." (Father of 54 year old daughter, Yateley)

"(On talking about how they felt) I felt fobbed off as the doctor said 'what can I do about it?' not helped and I was seeing locum after locum after locum and I have to say everything all over again." (Farnborough)



"He (GP) doesn't have enough hair!" (Farnham)

"I had contact with a senior doctor and it was quite a negative experience because he stated 'I don't know what you want me to do' which was very unhelpful and distressed my son who was listening and expected to get some support from my surgery. Eventually he referred us to a consultant at the hospital and I was told directly that they could not take on any new cases as the consultant was leaving. The consultant then prescribed medication which helped my son's anxiety." (Mother of a 10 year old son with autism, Fleet)

"Sometimes he's fine" (Farnham) asking about their GP

"We never had support from our GP which was any good. They gave medicine and shrugged him off." (Father of a 28 year old son, Farnborough)

"My GP doesn't seem to know what is being said about services which help people with learning disabilities. All my daughter's GP could do for her is to provide sleeping tablets to get my daughter to sleep in her bed (She sleeps on floors when she is not in her own bedroom), I don't blame them though." (Yateley)

"Doctor's fine" (Farnham)

"I get my blood taken and my blood pressure. I don't like needles" (Farnham)

"Not really, I have a learning disability and I told my GP my mental health is bad and they didn't listen. I ended up with the ambulance and police who are stretched to capacity and I desperately needed help." (Farnham)

"I get no support at all. I pay for my own psychologist and I have been asking for a support worker for 15 years. I can't cope alone. There needs to be longer term mental health

support as the short-term support was great but it suddenly ended. I feel like I am not a functioning member of society. My GP is brilliant though, I just wish they know more to understand how to help me." (Male, 45 with autism, Asperger's, dyslexia and severe mental health, Fleet)

"My wife would ask anyone in the street although she would not recognize a safe place but would go to a place she is used to." (Farnborough) Being asked of where they would go if they were scared or frightened

Appointments (How easy it is to get an appointment?)

"I needed to see a doctor and was given an emergency appointment quickly. He was very thorough with his examination and allayed my immediate worries." (Fleet)

"I was told to make an appointment with my GP in two weeks time. The next one I could book was a month away. And I found that my GP had a week off, why didn't I see someone else?" (Fleet)

"Not easy at all- difficult receptionist" (Fleet)

"Have to wait a month to see GP or up to a month at Fleet Medical Centre. It's quicker if there is an emergency" (Fleet)

"I may book an appointment before I need it so when I need it I can be seen quicker" (Fleet)

"Just long appointment time but my doctor is very good" (Yateley)

"Not as easy as it was but not bad. If there is something urgent, you can get one" (Yateley)

"Dentist is very good- they book it before I leave- it is good system for me" (Yateley)

"My daughter sees different GPs if she cannot see her own. It doesn't matter as she wants to get seen." (Yateley)

When was the last time you saw your doctor?

"Still waiting. It's been 4 weeks" (Fleet)

"Couple of weeks ago" (Fleet)

"A couple of weeks ago for sleeping tablets" (Yateley)

"I haven't seen my doctor for 8 years. I see my dentist and opticians. I'm seeing my dentist this Wednesday." (Farnborough)



Is it easy or hard to understand your doctor?

"Both- the jargon they use is hard. I always tell them it's hard." (Male, with autism and learning disabilities, Fleet)

"I had depression and went to my GP. They just told me to fill out a form and they didn't talk to me. Then from that, they prescribed me medication." (A male carer, Farnborough)

Do you feel involved in your care?

"I felt involved in my husband's care (He had a learning disability with mental health issues), the surgery was helpful, doctors, nurses and receptionist. During his final month, he was able to be at home and we were supported by the doctors, community nurses and care at home team. They all communicated with each other seamlessly and I never had to pass messages from one to another." (Yateley)



"My care is good. I think the NHS has to be a lot quicker to see someone." (Male, with autism, Farnham)

"I don't feel involved in my care- there is no care!" (Male with autism and Asperger's, Fleet)

"I feel involved in my healthy because they gave me Ritalin tablets to calm me down." (Male, 17, with autism and ADHD, Fleet)

"I like my doctor. He listens to me. He knows me. He gave my support around getting out and who to help me with my DLA and getting a house for me to live in. I live in my own house now. I go shopping with my support worker. Ask my dad, he will tell you." (Male, 51 with learning disabilities, Farnborough)

"I feel that my mental health is completely ignored" (Male, 45 with autism, Asperger's, dyslexia and severe mental health, Fleet)

"Annual Health Checks for my wife with learning disabilities is useless. The GP sits answering questions on the form. They only checked her blood pressure." (Husband of a female with learning disabilities, Farnborough)

Do you have any new ideas you would like to share with us to make health services and mental health services better for you?

"To sustain the services provided- my son wanted to go to a summer club but couldn't go due to support workers from the NHS could not be provided as there is lack of funds."

"121 support on a regular basis"

"Long term mental health support that is local"

"Social workers for people with learning disabilities"

"We need more choices and options"

"Most families do not know their options for support and help. YouTube to me is a great help. Videos are helping to access information and doctors should be thinking about this and about easy read formats for such as appointment letters."

"There should be a consistent plan in place for care as well as myself caring for her."

"My doctor to help more on my blood pressure and my tummy down a bit."

Why is it important to be listened to?

A key element of this project is to ascertain the best way to engage with communities in a sustained and effective way. The following comments were captured:

"I think it's important to be listened to because you need to feel understood to feel safe and if you're not listened to, then you can't be taken care of. They can't learn things just out of a text book, they need to understand things from a personal point. They need to listen to experiences and not just what a textbook says" (Aldershot)

"As a parent, I feel like a lone voice. It seems nobody knows what to do and she'll end up somewhere by default." (Mother of a female adult, Farnborough)

"The best staff members are those who listen to what she is asking. Those who listen and are autism aware are best- some staff are better than others." (Mother of a female adult, Farnborough)

"We have a good relationship with our GP, who has known my son since he was very young. But this is partly because we accompany him to all appointments and act as his 'translators' and explain his illness and how it affects him. Without us and our knowledge of our son, I hate to think how he would be able to interact with any aspect of his physical care." (Parents of a 33 year old son, Fleet)

"I feel I should've been told by my GP about the Equality Act and the power of attorney sooner. Or get trained on the implementation of Mental Capacity Act to act on the best decisions of their patients. If this happened in the first place, my son wouldn't have gone through all this pain (physical pain that was uninvestigated due to GPs' response of not being able to do anything because son cannot give consent). GPs needs to be trained." (Father of a 28 year old son, Farnborough)

"My wife cannot hold a conversation. The GP knows how to talk to a family member. It isn't obvious that my wife has a learning disability and GP talks to her and disregards me. GP should be talking to both of us so I can emphasise what she is saying." (Husband of a wife with a learning disability, Farnborough)

We also attended other events to give us an idea of what issues were happening either locally and nationally. This gave us an opportunity to access other information that may be of relevance to the project. Groups and events attendee include:



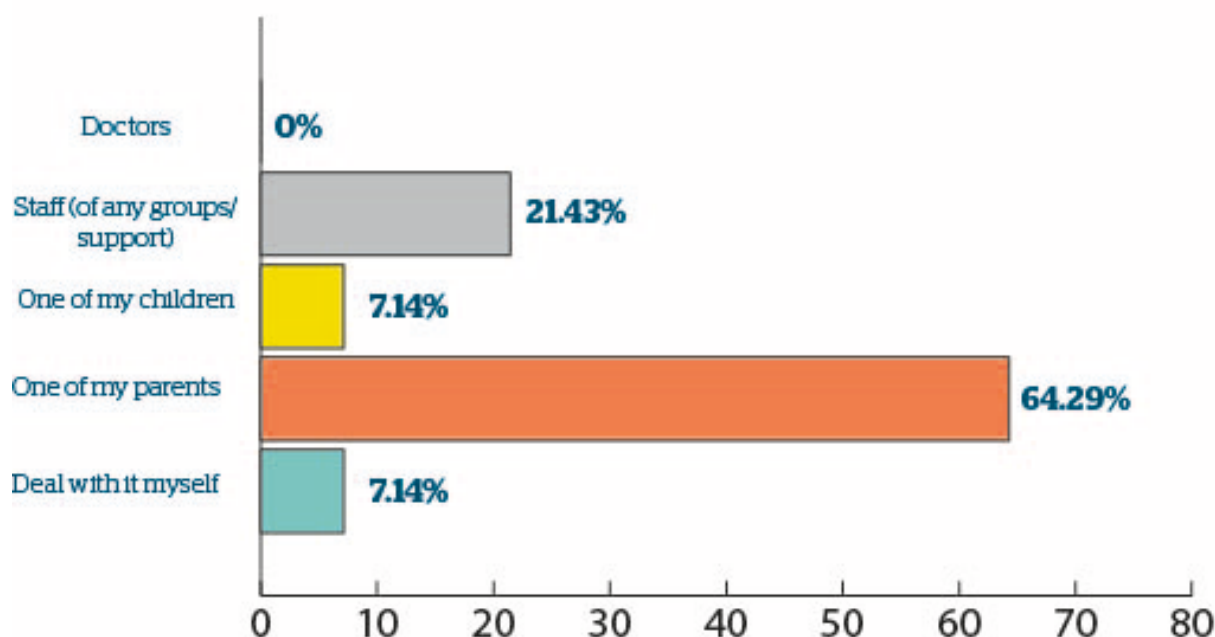
- Building up the right support for people with learning disabilities: one year on
- SHIP TCP: Hampshire- planning Year 2 on the successes and changes
- Blue Local Implementation Group
- Community Cash Fund: South Hampshire National Autistic society
- Post 19 Group
- Voice- Rushmoor
- Better Local Care
- Consultation on Autism and Mental Health- National Autistic Society
- Patient and Public Engagement Group
- North East Hampshire & Farnham and Surrey Heath Mental Health Forum
- Carers Hub: Yateley, Farnborough and FoCus

Feedback Analysis

The key findings from our engagement can be seen below:

- From 5 different towns, feedback shows that 2 out of 40 people with a learning disability have had a health check every year. People with learning disabilities often have difficulty recognising illness, communicating their needs and using health services. The annual health check is also a chance for the person to get used to going to their GP practice, which reduces their fear of going at other times.
- Annual health checks have been proven to improve health outcomes for people with learning disabilities. They consistently lead to the detection of unmet, unrecognised and potentially treatable health needs. (*Department of Health*)
- People with learning disabilities face serious health inequalities that health services have a duty to reduce. One practical step that GPs can take is to offer good quality health checks on an annual basis.

Who do you ask for help when you feel low or sad?

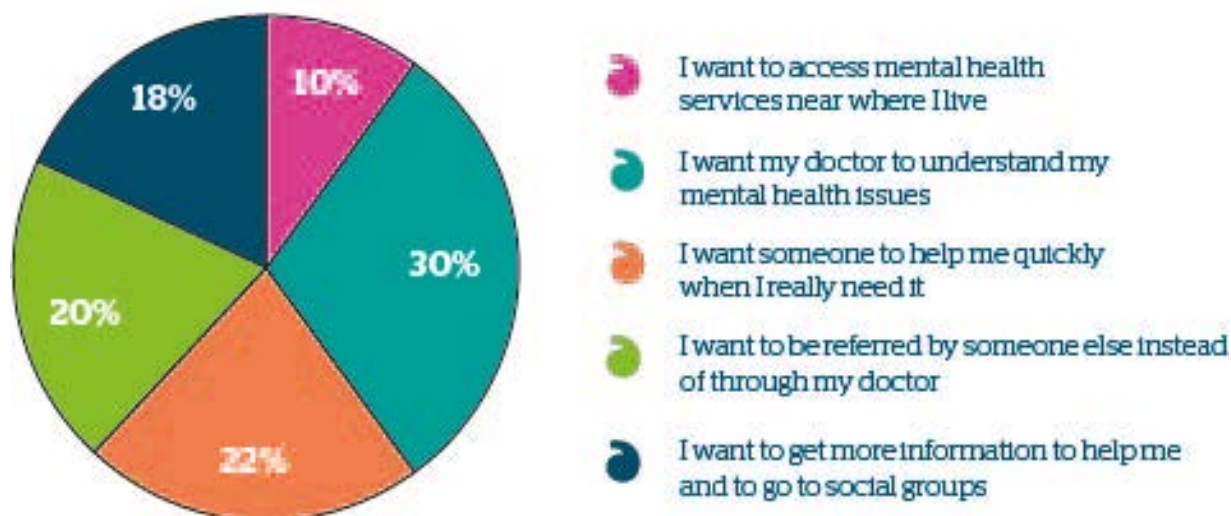


64.29% of people with learning disabilities ask their parents or children for help if they felt low or sad.

One responded "I don't know who to ask" (Fleet)

Though the data shows that they do not ask GPs for help, 33% said they felt their doctor knows enough about them to help. And 78% felt that their doctor understood their needs.

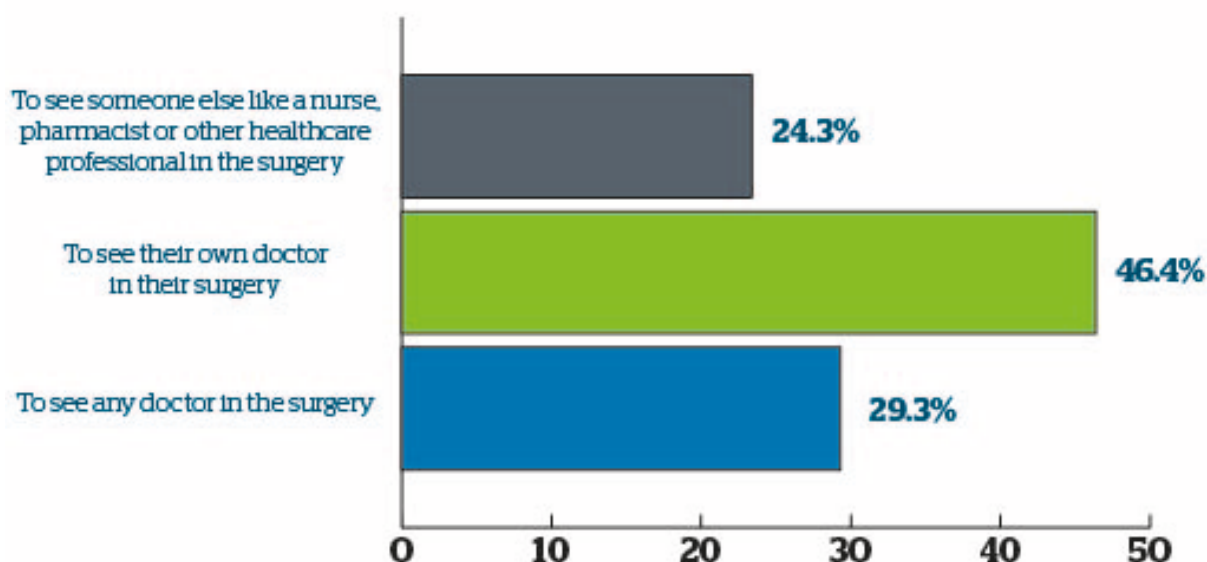
Feedback shows which they felt was most important to them



78% of the feedback shows that their doctors understood what their needs were

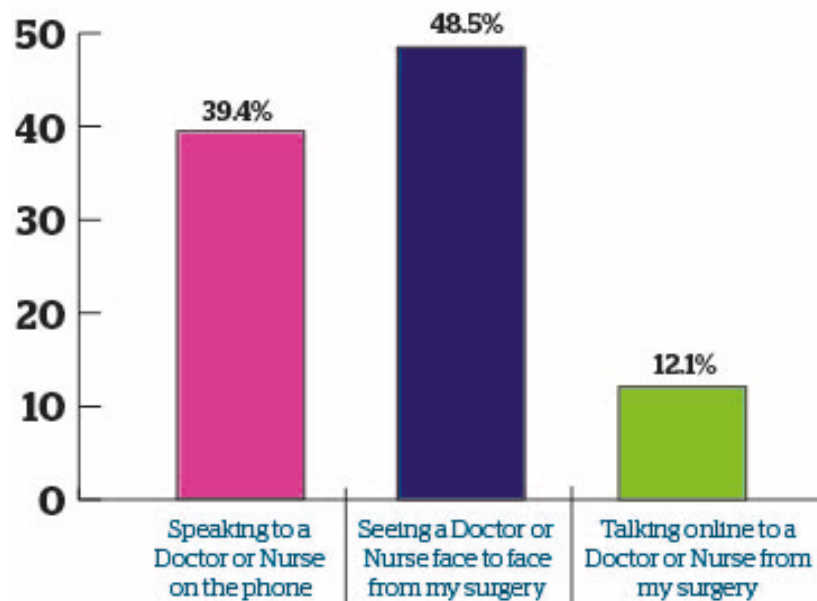
"The best staff members are those who listen to what she is asking. Those who listen and are autism aware are best- some staff are better than others." (Mother of a female adult, Farnborough)

People with LD preferred...



Physical health affects our mental health, and vice versa. (DWP)

People would prefer to get their advice by...



"I haven't seen my doctor for 8 years. I see my dentist and opticians. I'm seeing my dentist this Wednesday." (Farnborough)

"I like my doctor. He listens to me. He knows me. He gave my support around getting out and who to help me with my DLA and getting a house for me to live in. I live in my own house now. I go shopping with my support worker. Ask my dad, he will tell you." (Male, 51 with learning disabilities, Farnborough)

"GPs need training around learning disabilities, understanding but mostly importantly with empathy." (Female, 19 with a learning disability and BPD, Aldershot)

"More specific training around learning disabilities not generalised stuff. If GPs do not know, they need to keep training not forget about it and call the next patient in." (Father, Aldershot)

"I don't want to live in a doctor's surgery" (Farnborough)

"I am forced to get in a situation I don't want to" (Farnham)

"Trying to calm me down in the waiting room did not help but was helpfully met"

"My daughter has a mental health diagnosis. She still has, but in February she was diagnosed with autism. They realised that her issues such as meltdowns were related to autism. Before they thought she had borderline personality disorder (BPD). The community consultant is fairly clear that her behaviours are autism related and my daughter agrees. The Inpatient consultant thinks it's BPD, I don't think he has much understanding of autism. This is making it very difficult to get help and make progress." (Farnborough)

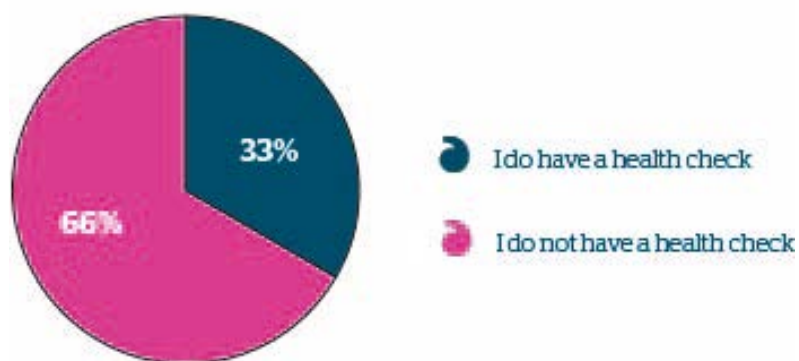


"We need practices to be more LD friendly. GPs need time and skills to implement this. They need to listen to carers and their family members, treating them as equals." (Farnborough)

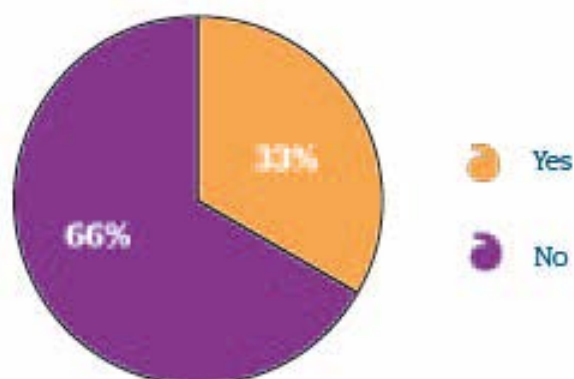
"Coping strategies given, before leaving an appointment- tools & techniques to use, if they don't know- print them" (Aldershot)

"Some options are not suitable for people with social anxiety" (Aldershot)

Health checks



Have you used the Wellbeing Centre or Safe Haven in Aldershot?



Response from Professionals (Ongoing)

Throughout the project we have engaged with professionals working with people with LD and their carers.

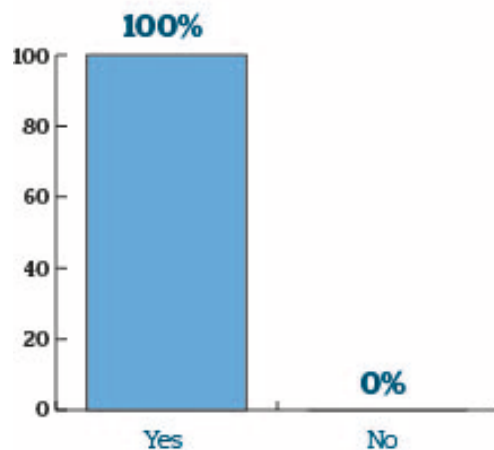
We also had the opportunity to present these findings to the North East Hampshire team of GPs, 55 GPs on the day, were given more information of accessible information to support

them in their work (See Appendix) and they also had the opportunity to answer five questions in a poll;

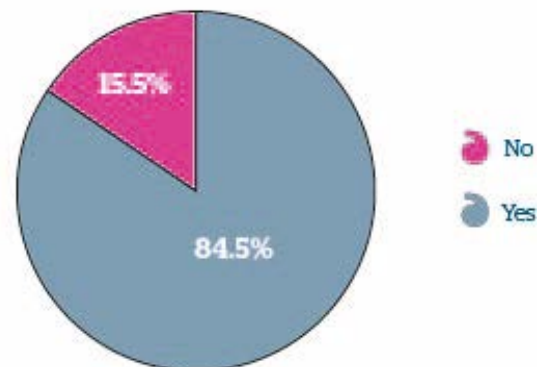
- Are your patients with LD known to your practice?
- Do you feel confident to do a Mental Capacity assessment?
- Is your Practice or Surgery conforming with the NHS Accessible Information Standards?
- Do you feel confident in signposting to LD services?
- Do you do Annual Health Checks for your patients with LD?

These are the results;

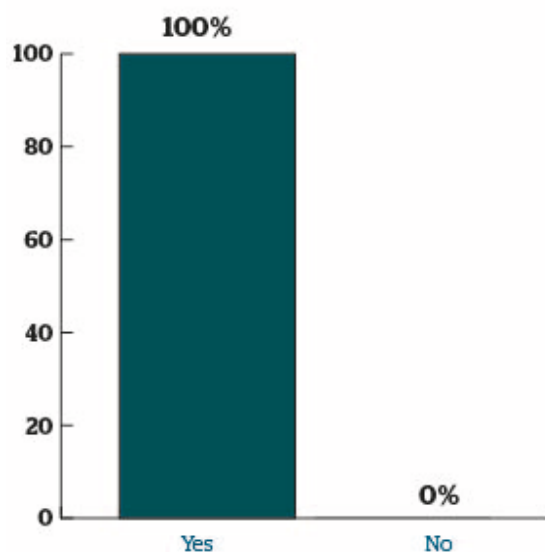
Are you patients with LD known to your practice?



Do you do Annual Health Checks for your patients with LD?



Is your Practice or Surgery conforming with the NHS Accessible Information Standard?



Their comments were recorded by an exit survey from the NHS North East Hampshire and Farnham Clinical Commissioning Group;

"Lesley Rosling was very passionate and knowledgeable"	"Healthwatch was great"	"I enjoyed the quiz"	"Useful information and stats. Template was good"	"The Healthwatch info went well"
"Choose a better venue"	"Venue too cold"	"Useful to have templates"	"Really useful info re new plate for LD assessment"	"Food and drinks not great"
"I liked the stats, videos and template"	"Good to hear about the new services available"	"Difficult to hear"	"Helpful template and 'My Health Check' "	"Good speakers and interesting information"
"I learnt a lot more needs to be done to make services available for people with LDs"	"Slides too long, speakers just reading off them"	"I will be introducing the Template to our practice"	"I learnt about the health statistics of LD patients"	"Use a working microphone"
"Going to look at a dedicated member of staff to deliver LD and increase appointments"	"Very good overview"	"I learnt what support is available for clinicians and patients in our area"	"In our practice we're now going to start annual health checks"	"It would have been good to know local opticians/dentists that specialise in LD patients"
"The videos were great"	"I learnt the importance to active listen to LD"	"In our practice we will use more signage, posters"	"I liked the videos and it was good to get useful contacts"	"I learnt about the differences between Learning Disabilities & Learning Difficulties"
"We will be more proactive in our practice inviting LD pt's in for a health check"	"Please send us electronic copy of pre-hc questionnaire"	"Please can Healthwatch send us invite packs to increase engagement"	"Interesting content"	"New EMIS template looks great"
"We will include the new template and have longer appointments for GPs"	"Interesting and informative training session"	"Great speakers"	"Statistics on quiz were surprising "	"We plan to lengthen GP appts from 10 minutes in our practice going forward"

Summary

Due to the time constraints of the project, Healthwatch can only give a snapshot of the daily issues faced by people with LD and/or autism, particularly around mental health as it is a broad topic and can affect individuals in different ways. These findings only show what Healthwatch could identify and evidence for the report.

The key themes highlighted are;

● Referral Processes

- When at crisis point, some people reported that they had to wait for their referral to be processed. They expressed that there should be preventative services in place to support them while waiting for the support and suggested that if this was already in place, they would not reach crisis point.
- It was also noted that if they had an alternative contact to mental health services, they would access this rather than going through their GP, and having more time with the said service. Many have said "Wouldn't it help taking the pressure off GPs?"
- GPs felt that their patients were known to their practice however it is understood that they do not feel confident in signposting to an appropriate LD service that may be beneficial to the impact of the patient's mental health. The GPs may need more support for this to be sufficient.

● Resources

- Many of the individuals have said there is either too little resource or gaps
- GPs felt that their surgery or practice is conforming with the NHS Accessible Information Standards but they felt they are not confident enough in signposting to LD services- perhaps this may need to be considered why this is the case. Perhaps there are not enough resources provided to them. The exit survey feedback showed that the templates such as the invite pack were found useful and GPs asked for further information. Further information is available in Appendix B.
- Parents/Carers are a vast resource that GPs and Mental Health services may underuse and they are key to everyday aspects of the individuals' life

● Parents/Carers

- This has been highlighted several times throughout Your Voice Counts- parents and/or carers have been found to be a big part of many people with learning disabilities' lives. They are present daily and understand the issues and impact of any situations that would be had on the individual.
- Carers felt that they were not offered mental health support from the GP, or had information from the GP about where they could find out more information and again, this may be the case of the GPs not having the resources available.
- Parents/carers felt that they were not included in the conversations between the patient and GP, and not being given the opportunity to highlight any issues that the patient themselves cannot communicate. This is another way of being able to locate any issues and therefore make it time effective for the GP, the carer and especially the patient themselves.
- Many parents and carers emphasise the importance of being listened to, particularly for those who are acting as an advocate for the individual.

● Mental Health

- Training was a key theme through individual discussions. People felt that some GPs needed to be trained further to support people in need of mental health support or that needed extra support in communicating effectively.
- A few people have said that they would like access to mental health services in Fleet locality, as they felt there was no appropriate resources available or not known.
- Parents and/or carers felt that their mental health is ignored or they have not had the opportunity to have some respite support.
- Nearly half of the GPs in the training session felt that they were not confident to do a Mental Capacity assessment on their patients with a learning disability.
- 84% of GPs say they do the Annual Health Checks for their patients with LD, these are vital in picking up any issues, particularly around the individual's mental health.
- Other
 - Hart District Council is in the process of signing up to the Local Authority Mental Health Challenge. This national initiative, launched by a partnership of charities and The Royal College of Psychiatrists, encourages and supports councils to promote better mental health in their area. They have been identifying a priority to focus on in 2017.

The one key theme highlighted throughout all engagement was the individual having a choice. Some people felt they were not included in their care and felt that they had to go along with 'what the professionals say', with no input to how they feel about the options given.

Another theme highlighted was the perceived categorisation of people with autism. They felt that autism was just put into the learning disability category and the services available were not adapting to the understanding of the needs. Individuals wanted clear, simple to follow instructions and when appointments are made with a specific time, to be followed through as they sit in the surgeries' waiting room, becoming more anxious. One even suggested a small booth or private room that they could wait in as it would reduce heightened sensitivity.

Recommendations

These recommendations were given to GPs on their training session, though this list is not exclusive of any other services supporting people with a learning disability and/or autism.

- Don't ask leading questions.
- Give enough time to answer
- Listen to the patient or their carer for their adjustments, following the NHS Accessible Information Standards
- Include carers- they may hold vital information that patients cannot communicate to you
- Give your patient and yourself enough time for an appointment
- Ensure you book Annual Health Checks for your patients
- Signpost when necessary to appropriate services such as the Citizens Advice Bureau for more non-medical information

Further recommendations;

- Give the person with a learning disability and/or autism a choice. Asking this question gives them the opportunity to speak up to say what they would like or need.

- Notify the person with a learning disability and/or autism of what will be happening next. Whether it is another appointment or referral process- a sense of what is happening helps to reduce the anxiety during the waiting period.
- A small booth or quiet room to be made available for those with heightened sensitivity
- Parents and/or carers to be supported more;
 - Parents/Carers being identified and registered as carers with their GP practice
 - Registered carers should be given the opportunity for a carer's assessment
 - Carers to be offered mental health support from the GP, alternatively the GP signposts to the appropriate resource
 - Parents/carers to be included in the conversations with the patient and GP, and give them an opportunity to highlight any issues that the patient themselves cannot communicate
- Ensure that reasonable adjustments are included in the individuals' support- such as easy read versions (This is also complying with the NHS Accessible Information Standards) for;
 - Benefits of a health check
 - Appointment letters and/or call the day before the appointment
- GPs to undertake specialist training (Or a recap) on:
 - Mental Capacity assessments
 - NHS Accessible Information Standards (Resource is also found in Appendix C for patients)
- To provide GPs with resources
 - such as LD services in their locality
 - voluntary and community groups to signpost to
 - This could be led to a social prescribing model
 - Contact information for day centres
 - Contact information of organisations for parents and carers
 - To provide GPs with resources, such as the pre-visitation pack which gives each patient an idea of what to expect on their visit. This would result in lowering some anxiety
 - For all Practices and Surgeries to comply with the NHS Annual Health Check programme as it is a requirement made by Public Health England and NHS England. For further information please see Appendix D
 - For all Practices and Surgeries to provide easy read documents or in other formats such as video/audio.

What's next?

The second phase of Your Voice Counts is focusing on Adult Mental Health. The Citizens' Advice Bureau have already rolled out the surveys in Hart and Rushmoor area.

We will be bringing a group together to discuss future engagement with North East Hampshire and Farnham Clinical Commissioning Group, strengthening the relationship between both parties.

If anyone is interested in participating, please contact Fi Biggs.

Key contacts

Blue LIG Group

Florence Garland
Adults' Health and Care
Hampshire County Council
Telephone: 01962 847249
Email: Florence.garland@hants.gov.uk
Website: <http://www.hampshirelearningdisabilitypartnershipboard.org.uk/>

Hart District Council

Liz Glenn
Health and Policy Project Officer
Hart District Council
Telephone: 01252 774228
Email: emma.abdulaal@nhs.net
Website: www.hart.gov.uk
Twitter: [@HartCouncil](https://twitter.com/HartCouncil)
Facebook: [/HartDistrictCouncil](https://www.facebook.com/HartDistrictCouncil)

Parents and Carers Hub

Ian Penfold
Community Ambassador and Parent

Happy, Healthy At Home (Vanguard)

Caroline Martinez
Community Ambassador Coordinator
Happy, Healthy at Home (NE Hants & Farnham)
Telephone: 01252 335573
Email: nehfccg.ambassadors@nhs.net
Website: www.happyhealthyathome.org
Twitter: [@NEHFCCG](https://twitter.com/NEHFCCG)

The National Autistic Society South Hampshire Branch

David Carter MBE
Branch Officer
Hampshire Autism Voice
Email: dc@hampshireautismvoice.org.uk
Website: www.shantsnas.org.uk
Twitter: [@Autism](https://twitter.com/Autism)
Facebook: [/HampshireAutismVoice](https://www.facebook.com/HampshireAutismVoice)

**Compiled by Fiona Biggs
Engagement & Project Officer
January 2017**

References

'Health Inequalities and People with Learning Disabilities in the UK: 2011' Sue Turner, Carol Robinson, Improving Health and Lives Learning Disabilities Observation. Improving Health and Lives is the Learning Disability Public Health Observatory - www.improvinghealthandlives.org.uk - a three year project funded by the Department of Health

'Hear my voice: healthcare' Mencap

'My Face, My Story' Healthwatch Hampshire

http://www.healthwatchhampshire.co.uk/sites/default/files/my_face2c_my_story_-_learning_disabilities_report_2016_2.pdf

NHS Information leaflet for Annual Health Check: Easy Read

www.healthcheck.nhs.uk/document.php?o=789

Department of Health, Six Lives: Progress Report on Healthcare for People with Learning Disabilities (2013)

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212292/Six_lives_2nd_Progress_Report_on_Healthcare_for_People_with_Learning_Disabilities_-_full_report.pdf

NHS England, Making health and social care information accessible (July 2015)

<https://www.england.nhs.uk/wp-content/uploads/2015/07/access-info-upd-july-15.pdf>

'Health Checks for People with Learning Disabilities: Implications and Actions for Commissioners Evidence into practice report no. 2' Sue Turner, Carol Robinson, Improving Health and Lives Learning Disabilities Observation

'Annual Checks for People with Learning Disabilities' NHS Choices

'Mencap Briefing: Benefit changes: the Welfare Reform Act 2012' Mencap

Jonathan Beebee, Nurse Consultant, PBS4

Parents' Voice, parentvoice@roseroad.org.uk

'Shortage of learning disability nurses putting thousands of lives at risk - Mencap' National Health Executive 4th November 2014

Building the right support

<https://www.england.nhs.uk/wp-content/uploads/2015/10/14-nat-imp-plan-oct15.pdf>

MiXiT! theatre group

Virtual Smart House

<http://www.hftsmarthouse.org.uk/#prettyPhoto>

<https://crm.disabilityrightsuk.org/benefits-information/care-act-guide>

'A small-scale investigation of hospital experiences among people with a learning disability on Merseyside' Adam Peter Dinsmore June 2011

Learning Disability Partnership Board T17 Transform presentation

Appendix A

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224805/NHS_Health_Check_implementation_review_and_action_plan.pdf

Appendix B

Resources for People with Learning Disabilities

There are resources that GPs can use to reduce health inequalities for people with learning disabilities.

Learning Disability Liaison Nurse (Surrey and Borders)

Can help doctors and nurses to understand how to complete annual health checks and provide advice and training on how to give better care to people with a learning disability.

Resource links

Includes

- Learning Disabilities Friendly GP Surgeries
- Annual Health Checks
- ABCD Checklist for practices
- Easy read invitation to Annual Health Check example
- Easy read Annual Health Check preparation documents

<http://www.southernhealth.nhs.uk/services/learning-disability/strategic-health-facilitators/>

- Provider of books, services and training for people who find pictures easier to understand than words including people with learning disabilities including a free app to support communication

www.booksbeyondwords.co.uk

Mental Capacity Resources

- Mental Health Rights Act- Easy Read version
<http://www.nhs.uk/NHSEngland/AboutNHSservices/mental-health-services-explained/Pages/easy-read-mental-health-act.aspx>
- MCA and National Mental Capacity Forum (Video)
<http://www.scie.org.uk/mca-directory/forum/video.asp>
- Mental Capacity Act (MCA) tailored for you
<http://www.scie.org.uk/mca-directory/mca-tailored-for-you/index.asp>
- Mental Capacity Act
<http://bhamsouthcentralccg.nhs.uk/health-services/mental-capacity-act>
- GP Resource Pack
<http://bhamsouthcentralccg.nhs.uk/publications/1091-gp-resource-pack>

Helpful Organisations for parents/carers

- Contact a Family (Children)
<http://www.cafamily.org.uk/>
- Hft
<http://www.hft.org.uk/>
- Blue LIG group (Basingstoke, Hart and Rushmoor Local Implementation Group)
www.hampshirelearningdisabilitypartnershipboard.org.uk
- FoCUS (Forum of Carers and people who use our services) SaBP NHS
www.sabp.nhs.uk/focus

Local Day Services

- Bells Piece (residential home and day service in Farnham)
<https://www.leonardcheshire.org/support-and-information/disability-care-and-support/care-homes/bells-piece>
- Parkside
<https://www.parksidealdershot.co.uk/index.php>

Appendix C

Name: Address: ID number:	
In accordance with The Accessible Information Standard (SCCI 1605 (Accessible Information)) please accept the below as formal notification of my information and communication preferences.	
I communicate using (e.g. BSL, deafblind manual):	
To help me communicate I use (e.g. a talking mat, hearing aids):	
I need information in (e.g. braille, easy read):	
If you need to contact me the best way is (e.g. email, telephone):	

The Accessible Information Standard (SCCI 1605 (Accessible Information))	
Providers of health and adult social care services have new duties to support those who access their services who have sensory impairments and/or learning disabilities. They must:	
<ol style="list-style-type: none">1. Identify the communication and information needs of those who use their service;2. Record the communication and information needs they have identified;3. Have a consistent flagging system so that if a member of staff opens the individual's record it is immediately brought to their attention if the person has a communication or information need;4. Share the identified information and communication needs of the individual when appropriate;5. Meet the communication and information needs identified.	
For more information visit: https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/	

Annual Health Checks for People with Learning Disabilities

One step that GPs can take to reduce health inequalities for people with learning disabilities is to offer good quality health checks on an annual basis.

Who can help a GP practice ensure all their patients with learning disabilities have annual health checks?

Health Facilitators (Learning Disability Nurses), who can help doctors and nurses to understand how to complete annual health checks for people with learning disabilities and provide advice and training on how to give better care to people with a learning disability.

<http://www.southernhealth.nhs.uk/services/learning-disability/strategic-health-facilitators/>

Resources include:

- Learning Disabilities Friendly GP surgeries
- A new poster about Annual Health Checks
- ABCD Checklist for Practices
- Easy read invitation to Annual Health Check example
- Easy read Annual Health Check preparation documents
- 'Your next patient has a Learning Disability'
- 'Meeting the needs of patients with Learning Disabilities'

Other resources

Books beyond Words - www.booksbeyondwords.co.uk

Beyond Words is a provider of books, services and training for people who find pictures easier to understand than words including people with learning disabilities.