

Annual Health Checks and how best to support people with a learning disability to attend GP and hospital appointments

Q & A session – 1st December 2020

Professionals:

Dr David Chapman: GP in Oxford City, Clinical Lead for Mental Health, Learning Disability & Autism for the Oxfordshire Clinical Commissioning Group (OCCG)

Simon Jones: Learning Disability Nurse Consultant for Oxford Health covering the Community Teams and the inpatient team at Littlemore Hospital

Stephanie Ross: Learning Disability Liaison Nurse across the Horton, the Churchill, John Radcliff and Nuffield Hospital in Oxfordshire

Q1. How do we know whether people with a learning disability are on their GP's register? What is the process for getting someone registered?

Dr David Chapman: There is not a formal registration process but anyone who has a learning disability or supports someone with a learning disability can approach their GP surgery to ask to be registered. The GP would look at each case individually. There appears to be a gap of the number of people registered with GP's and the percentage expected. GP's often wait to see where there has been a diagnosis in the past usually through paediatrics or secondary care adults. However, paediatricians do not often use the word learning disability and it is therefore trickier for GP's to just put that down as a diagnosis on their books as learning disability can be complicated and hard to define, particularly for those with a milder learning disability. GP's use a list to work out who does have a learning disability but it can be complicated as GP's do not always have enough information. Part of that information is how a person is functioning in the community and in their lives and if that person feels that they are functioning satisfactorily they may not want that label of having a learning disability or to be registered as learning disabled with their GP practice. However, anyone who has good reasons for wanting to be on the learning disability register should be able to register.

Q2. Do all GP Practices have a Learning Disability Register (LD Register)?

Dr David Chapman: Yes, it happens automatically due to the way data is entered in to the GP's system. Nearly every bit of data like diagnosis is given a SNOMED code – so everyone on the learning disability register will have a SNOMED code saying they are on the LD Register.

Q3. What are the benefits of being on the Learning Disability Register?

Dr David Chapman: The patients should automatically get notified about their annual health check. It's also good to flag up when a patient who is calling the surgery for an appointment is on the LD Register as the whole essence is about making reasonable adjustments for that person which may not happen if that person is not 'labelled' as having a learning disability. When also looking at complicated illnesses such as a physical illness, discussions can be complicated. A person's information is confidential to themselves but when a person has a learning disability the GP may need to be looking to other people to support that person when having that conversation. This is

particularly important when having discussions about illnesses such as cancer or when they go in to hospital.

When going in to secondary care, if a person does not have a label on the LD register it is much harder for Doctors in secondary care to pick up that information as transfer of information for patients is not a seamless process.

Simon Jones: Someone who is on the LD Register is also entitled to the seasonal flu vaccine

OxFSN: There is an assumption that if your child attends a specialist school, they would automatically go on the GP register but that is obviously not the case.

Dr David Chapman: No, this is not the case although one of the questions GP's would ask if someone was asking to be added to the LD register would be 'Which school do /did they attend?' as this would be an indicator. GP's themselves have to spend some time working out whether the person themselves wants to be on the LD Register which is crucial that they are asked. If they are functioning well in the community which means different things to different people is it right to put them on the LD Register

Q4. My family members health check is in a few days' time but because of COVID I am not able to support her to her appointment. I am only able to face time and discuss the appointment with her. I was surprised that this was going to go ahead without any involvement or input from me even though I have been her advocate for 35 years. She has 24/7 support but it is quite new to her and the support staff do not know her so well. My family member was also on the LD Register and she used to get notifications from her GP to attend an annual health check which was in Easy Read but it is not happening now. How have we and probably other people slipped through the net?

Dr David Chapman: It is not written in stone as to how patients are invited to attend an annual health check although receiving a reminder from the surgery is helpful. If someone asks to have a health check and they need one, they will be invited to have one. There are 70 different GP practices in Oxfordshire and they all will do things differently.

The tricky point you have raised is that as her family carer, you know your daughter best, and because of COVID you are not able to go along to her annual health check which does present a problem. You could see if the GP can have a conversation with you before seeing your daughter. However, people are currently being placed in risk groups for CoVID and practices are as safe as they can be, as both GP's and patients (where possible) are using full PPE so in some practice's family carers are coming in. It would be best to have a family carer who knows a patient best at the appointment with them. The problem that many GP's have is that a lot of their patients who have a learning disability are in supported living and are often accompanied to their appointments and health checks by support workers who do not know the patient very well which makes a health check much harder.

OxFSN: This is an issue that also needs to be discussed with the support provider so that they are aware when the family carer wants to attend their family members health check or if the family carer is happy that their family member is supported by a staff member who knows them really well.

Q5. At what age does my child change over from automatic parental involvement to being treated as an autonomous individual in appointments?

Dr David Chapman: It is not a question of being an adult or a child, it is to do with capacity. Every capacity is meant to be considered for every issue but one of the problems with capacity is that it depends on which question you are asking and whether the person has capacity to understand that information. Capacity is about giving information to a person, that person being able to understand that information to be able to replay back the information you are talking about and then making a decision. If they can do all that, then they have capacity for that decision.

Simon Jones: It is also important to point out that irrespective of someone's age the law requires us to assume they have capacity until proven otherwise.

Q6. Can you have a zoom type GP call to include a family carer to reduce risk or allow those who are living separately to the people they support?

Dr David Chapman: There are two different issues here.

It would be possible to have a conversation over the telephone or zoom with some family carers. However, in terms of doing the health check remotely this is slightly controversial at the moment as the health check is supposed to involve a physical examination which would not happen with zoom. During COVID times we do need to be as practical as possible which means that some health checks could be done via zoom. There are certain things that GP's sometimes prefer to do during an annual health check including a urine test and a blood test which will be difficult to do remotely but if all parties feel a health check could be delivered as remotely as possible then this would be ok during COVID as doing at least 80 % of the health check

A lot of people these days also have their own technology such as weighing scales and blood pressure machines so it may be possible to do some of this at home which is what a lot of routine patients are doing anyway.

Dr Chapman's personal opinion is that as practices are deemed to be safe places and all staff and most people coming in wear PPE that a fairly standard health check should be able to be carried out although he recognises that it is not always easy for the family carer to attend for various reasons.

If families think it is important that their family member has a health check or it is due and they have not been called for one, they should call the practice.

Simon Jones: It is more difficult during COVID times to do an annual health check but equally it is more important than normal for an annual health check to be carried out as it is a vulnerable group of people who needs the checks done so it is important to try and find a way.

Q7. What should a good health check look like? How long should it take?

Simon Jones: One of the difficulties is that there is not a standard annual health check that GP's have to follow and it is left to the GP's discretion. However, as working with a group of patients who often find communication difficult, it is important to go that extra mile and do as many tests or examinations as possible otherwise the person runs the risk of having undiagnosed health issues that carry on for years. He, personally thinks it would be impossible to get to that level of detail in 20 minutes. A lot of practices subdivide the work between the practice nurse and the GP. Where Oxford Health LD have been involved with a patient in doing a health assessment with the community teams, they are happy to share that with the practice to save them having to ask the same set of questions.

The [Cardiff Health Check](#) is a fully comprehensive document that includes all the areas that you would expect to be covered in an annual health check.

Dr David Chapman: Many GP's have had people with a learning disability as a patient at their practices for many years who have visited for other problems quite regularly. It may be that they know those patients very well compared to those who visit only once a year and it could be the latter group where things could easily be missed. All practices will do checks slightly differently so it is not about a set time, more a question of does it achieve the purpose it is meant to achieve?

Simon Jones. Important to note that just because a patient may see their GP regularly it does not mean that they have had an annual health check.

Family Carer: Having moved into Oxfordshire a year ago, this was the first time my daughter (16 at the time) was offered an annual health check, it was so well explained by the surgery as I had no idea what it was for as she sees so many specialists, but I found the appointment really useful and they sent us information about it beforehand too.

Q8. It can be difficult for those individuals who are anxious about visiting a GP surgery when their annual health checks are set up as two separate appointments with the nurse practitioner and the GP. What can be done about this?

Dr David Chapman: This is about a surgery using **reasonable adjustments** and adapting. Part of the health check is about working out the reasonable adjustments and this is an issue that can be raised then to see if it is possible for the two appointments to be booked simultaneously. If this issue has never been raised with a practice, they may assume that they are doing the right thing which can be true about a lot of reasonable adjustments.

OxFSN: There are good examples of where reasonable adjustments have been made including GP's coming out to see a patient in the car when they have refused to get out of the car or visiting a patient at their home as they cannot make it in to the surgery. Family Carers don't always know that they can ask for reasonable adjustments to be made.

Simon Jones: Health Care providers have a legal duty to provide reasonable adjustments. It is a patients' right and a practices responsibility to meet those rights.

OxFSN: Not many family carers are aware that their family member is entitled to an annual health check from the age of 14. Maybe we need to be doing more to promote that information across schools to advertise that more.

Stephanie Ross: Making reasonable adjustments is a fair bit of the work that the LD Nursing team do. It is very individual as to what somebody may need and what works for one, may not work for another. There is often a need to find a compromise so it is important to get in contact and talk through about the things that someone may find difficult or the challenges they may have. The LD team get the clinicians to talk about what the normal process would be and then they start to tease out what might work for the person needing that extra support in that particular situation. It is often a case of starting with what you know might be issues, what you expect might happen and then think about what can be done differently. A reasonable adjustment can be all sorts of things. It might be about times and locations and reducing waiting times but it may also be something completely off the wall. Different things work for different individuals.

Q9. I have struggled over the years to get my GP and hospital to make reasonable adjustments. My son finds it incredibly difficult to enter any building he does not know. We haven't managed to get him in to a hospital for about ten years after a terrible experience. He is now 18 and I cannot physically take him. We had a GP appointment recently. I asked if they would come outside and the answer was no. What do I do about this?

Dr David Chapman: Sometimes I visit patients at home if they refuse to come to the surgery but sometimes, they do not want you to visit them at home which becomes very difficult. If someone is happy to be seen in the carpark and the family carer is in agreement then it would be a reasonable adjustment for a GP to come out and visit that person in the car. Would suggest asking that particular GP practice to reconsider.

Stephanie Ross: The LD Team are there to support families experiencing this situation and would work with all parties concerned to work through all the issues and explore what would work for that individual. Would need to consider safety and confidentiality but there are lots of places that a car can be driven to for consultants to meet in an outdoor environment. Should always follow the usual referral pathway of setting up an appointment, then email the LD Team on learning.disability@ouh.nhs.uk It is important to try and keep people following the usual pathway as much as possible so that they can think through all the different issues and tweak it where necessary.

Simon Jones: Oxford Health are working with OxFSN to look at ways to try and help people overcome their fear of medical establishments. It is very difficult but worth trying to do even when there isn't a problem so that later on if there is one, they have had some preparation. It is quite probable that at some point in their life, people are going to need to get blood work done or have vaccinations and the more preparation families can do for that to dispel some of the fears the better it will be.

Family Carer: My son had to visit the hospital last week. Even though I knew about Stephanie Ross, I did not connect her with the Churchill Hospital until someone reminded me that the LD Nursing Team cover all four hospitals. She was able to help me sort out COVID tests for my support staff and to adjust the time he

had to wait. My son who gets very anxious about visiting hospitals was taken to his appointment by his support staff who know him really well. I was really impressed by the nursing staff who were great and took their lead from his support staff. I couldn't believe that he was in and out within two hours having had a general anaesthetic.

Family Carer: We also had a very positive experience at the Nuffield, they made my daughter an appt at the end of clinic so there were no other patients and she wouldn't have to wait, plus we could wait in the car till she was ready to be seen as her health is very complex and vulnerable. This made such a big difference to her as she gets really anxious waiting.

Q10. I'm hearing through our local doctors that there is a supply shortage of the flu vaccine which is probably why people are struggling to get slots. As a family carer I would normally have had a call by now but haven't heard a thing!

Dr David Chapman: There are various shortages as the vaccines are delivered in tranches of three for the over 65's and two for under 65's. A lot more people turned up for their vaccines this year in the first tranche and as the GP's submit their orders a year ahead a lot of the vaccine was used up by people who would not normally turn up which caused a shortage. The vaccine is now being released for the 55 – 64-year olds so for anyone under 65 there should be enough vaccine around. Rather than waiting to be called, Dr Chapman recommends calling the practice as it changes all the time.

Q11. My son who is 16 is autistic with a learning disability and attends a special school for moderate learning disabilities. He has recently been very unwell and has now been diagnosed with anxiety and depression. I have not been able to get him seen by the learning disability team or CAHMS. My GP was amazing and made an urgent referral to CAHMS who have said the learning disability team will not see him. He has now been seen by the 'Getting More Help Team' and the Neuro Developmental Conditions team. However, the school also said they thought he needed to see the Learning Disability Team, he is on the GP's Learning Disability register, he has a number of different diagnosis, the social worker also felt he needed to see the LD team and he had been referred to the LD team and CAHMS by the 'Getting More Help team' in the summer. When I spoke to the LD Team directly, they told me he could not be excepted because he does not have a piece of paper with a learning disability written on it. This seems to be because a paediatrician could not get him to take an IQ test when he was younger. When asked who to get a diagnosis from, they were told by the LD team that they do not do diagnosis. The 'Getting More Help' team said that there was a gap in provision for teenage young men with autism who are falling through services and that this is a commissioning issue. Why is this a commissioning issue? What is the criteria for LD CAHMS and why are they not accepting that my son has a learning disability? Given that the GP is a crucial referral route in to these services, if they don't have the information to make that judgement where does a parent like me now go to get a diagnosis of Learning Disability in order to access learning disability services as there will be hundreds of people in the same position. It would be really helpful if there was some read across between GP surgeries and other services so that people like my son do not end up in an Assessment Treatment Unit (ATU) further down the line.

Dr David Chapman: I think this is a case where a GP would not be making a diagnosis. It would seem to fall squarely with CAHMS and the LD Team to make that diagnosis. This does not seem correct as how would people get in to the LD team in the first place as most of the referrals would come from CAHMS.

Simon Jones: We work with adults and get referrals there for people we have not come across before and the first thing we do is to assess if they have a learning disability or not.

Q12. When I phoned the GP for a flu jab for my son 22, I was told he isn't registered as needing one. What do I need to do to register him as he has a learning disability and is in the at risk group?

Simon Jones: The GP's are asked to err on the side of caution. You need to tell them that he does have a learning disability and therefore he needs a vaccination.

Dr David Chapman: There was a problem with the clinical system Emiss which was not flagging up people with a learning disability who needed flu jabs. If the person spoken to is a receptionist, they may not understand the process so make sure they know that your family member has a learning disability and that they are entitled to a flu jab.

Q13. What kind of adjustments can a family expect if the young person has Autism Spectrum Disorder (ASD) but doesn't have a learning disability but they might need very similar adjustments made in order to access any kind of health service?

Simon Jones: Anyone with a disability, and ASD counts as a disability, is entitled to reasonable adjustments

Dr David Chapman: It has nothing to do with a person having a learning disability, if they have ASD which is classified as a disability they are entitled to reasonable adjustments. It would help if you could articulate the sort of things they would need. It is a requirement that health services make reasonable adjustments for all people with disabilities.

Family Carer: COVID has highlighted a lot of this with young people being asked to attend appointments on their own rather than taking someone in with them.

Dr David Chapman: This should not happen. If someone is caring for a patient they should be allowed to accompany them so would suggest gently challenging this as long as the carer/patient is wearing the correct PPE unless the patient has issues wearing a face covering.

Q14. How does a hospital passport get uploaded so it is available at the hospital if someone is going in to hospital? Who should it be sent to?

Stephanie Ross: Please complete a Hospital Passport (which can be found [here](#)) and if possible, keep a paper copy to bring with the person if they need to come in. Once completed, you can email the Hospital Passport to learning.disability@ouh.nhs.uk.

The Learning Disability Liaison Nurses will save the Hospital Passport to the person's electronic hospital records, so that it is available to Hospital Staff should the person need to come in. We are working on exactly where we save it and increasing awareness of them, so feel free to say to staff that they can find it on "EPR, Powerchart".

Simon Jones: Similar to the Health Action plan this is a document belonging to the patient and is very helpful in 'short circuiting' the system if a person goes into hospital. Many LD patients will physically take a paper copy with them when admitted and this is very helpful. If the person has an electronic copy then this can be sent to the LD Liaison nurses at the hospital who will have it added to the persons electronic hospital admission records.

Q15. Is there a separate register for autism?

Simon Jones: No, the only way the GP will know that the person has autism is if that is recorded on the persons health record as a diagnosis.

Q16. A parent of a young person with Autism (without LD). How are services adjusted for people unable (due to their mental health) who can't leave home or struggle to see/speak to people

Simon Jones: The Learning Disabled patient is always entitled to "Reasonable Adjustments" being made to how their healthcare is provided. The practice should adapt how they offer the person healthcare appointments accordingly e.g., appointments at the very beginning or end of the day or when the waiting area is empty, they may also be able to offer home or virtual visits, etc. The Community Learning Disability

Service may also be able to help either to enable the person to access the GP practice or for a Learning Disability Nurse to see the person at home and undertake some of the health assessment work and send through to the persons GP

Q17. Is this health check separate to the one they get in school?

Simon Jones: Yes, but likely to cover the same aspects.

Q18. Why is it that once students turn 18 yet are still in education, leave their Paediatricians and go under a local GP who has no knowledge of that person at all in most cases. Surely, they should stay with a Paediatrician until they leave Education provision ... they used to do this in the Isle of Wight but this has now changed but would be so much easier really all round.

Simon Jones: We are currently working on how to make the transition from adolescent to adult services more integrated and do recognise that this can be an area of difficulty with sometimes a loss of continuity.

Q19. Health Action Plan – it is not automatically registered with a GP or Hospital. How do they get to know about it?

Simon Jones: The Health Action Plan (HAP) belongs to the patient and is not part of their NHS Health record. It is normally something the patient keeps with them. As with the Hospital Passport it is a very useful tool for helping other health professionals know about the person's health status, and for the patient to use to monitor their own health and health appointments. If the GP initiates treatments or investigations they will record that in their GP records for the person, but it's also helpful to note these actions in the HAP.

Some useful resources

Oxfordshire family Support Network (OxFSN)

The importance of Health Checks and what you can expect from your GP Surgery

https://www.youtube.com/watch?v=izv6Y_6cDQw

My Life My Choice Health Checks

<https://www.mylifemychoice.org.uk/pages/19-get-healthy-live-longer>

Books Beyond Words

<https://booksbeyondwords.co.uk>

Don't Miss Out (Mencap)

<https://vimeo.com/284168829>

Written Information (Mencap)

<https://www.mencap.org.uk/sites/default/files/2017-03/Mencap%20Don%2527t%20Miss%20Out%2015.03.17.pdf>

What to expect when you get a flu vaccine

https://www.youtube.com/watch?v=eZ1vDai8u5o&feature=emb_logo

What you need to know if you support someone with a LD to ensure they get better Healthcare

https://www.mencap.org.uk/sites/default/files/2017-02/2016.209%20Dont%20miss%20out_Supporters%20Guide_online%20version%20%28003%29.pdf

Contact

<https://contact.org.uk/news-and-blogs/parents-urged-to-get-young-people-with-learning-disabilities-registered-for-an-annual-health-check/>