**Improving the general health of people with learning difficulties in the UK: experiences of the implementation of Annual Health Checks**

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This paper offers a brief overview of the background to implementing a policy of offering Annual Health Checks (AHCs) to all people with a learning disability/difficulty[[1]](#footnote-1) in the UK. It outlines what has been developed through national policy and then offers an insight into the experiences of four people with learning difficulties in relation to understanding and accessing AHCs. All four people are members of The Lawnmowers Independent Theatre Company (ITC) a company that aims to lay solid foundations for people with learning disabilities to participate fully in their own society, shaping their own environment and controlling their own futures.

**Addressing general health needs: the UK experience**

We know from the literature that in the UK people with learning difficulties are 58 times more likely to die before the ag or 50 than the general population (Disability Rights Commission Report 2006). They experience the same range of health concerns as the general population but illness or disease which is likely to have been identified and resolved for people who do not have learning difficulties is more likely to be untreated (Lennox et al 2003, Felce et al 2008).

In 2007 Mencap, an organisation in the UK that aims to work with people with a learning disability to change laws, challenge prejudice and support them to live their lives as they choose, published a shocking report, Death by Indifference (Mencap 2007). This Report graphically demonstrated, through presenting the stories of six people who Mencap believe died unnecessarily, the unacceptable level of health care offered to people with learning disability. Mencap believed there was institutional discrimination within the NHS which had to be addressed. It highlighted the need for “healthcare professionals to realise the serious – even fatal – consequences of their lack of understanding”. (Mencap, 2007:1)

Following the Mencap report the UK Government commissioned an independent inquiry on access to healthcare for people with learning disabilities. It was chaired by Sir Jonathan Michael and looked at the general health of people with learning difficulties. Its findings included that:

* people with learning disabilities are more likely to have poorer general health than other people.
* they find it much harder than other people to access assessment and treatment for general health problems that have nothing directly to do with their disability
* there is insufficient attention given to making reasonable adjustments to support the delivery of equal treatment for people with learning difficulties
* parents and carers of adults and children with learning difficulties often find their opinions and assessments ignored by healthcare professionals, even though they often have the best information about, and understanding of, the people they support,
* health service staff, particularly those working in general healthcare, have very limited knowledge about learning disability and are not familiar with what help they should provide
* partnership working and communication between different agencies providing care, between services for different age groups, and across NHS primary, secondary and tertiary boundaries was poor for services for adults with learning disabilities.

Michael found that although there were examples of good practice “witnesses described some appalling examples of discrimination, abuse and neglect across the range of health services” (Michael, 2008:7). Michael had demonstrated that whilst there were examples of excellent practice in a number of key areas good practice was found to be patchy and, where it did occur it it seemed to be as a result of the energies of people battling against the odds rather than to systems designed with people with learning disabilities in mind. The evidence had shown that there was “a significant gap between policy, the law and the delivery of effective health services for people with learning disabilities” (Michael 2008:53). The combination of the Mencap Report (2007) and the Michael Report (2008) meant that the health of people with learning difficulties could no longer be left to the vagaries of local practice. The Michael Report ended with a series of recommendations to improve practice, one of which being that the Department of Health should immediately amend the Standards for Better Health (2004), a set of standards that monitored NHS to include an explicit reference to the requirement to make ‘reasonable adjustments’ to the provision and delivery of services for vulnerable groups. More specifically it was recommended that Primary Care Trusts (PCTs[[2]](#footnote-2)) should be directed to secure general health services that make reasonable adjustments for people with learning disabilities through a Directed Enhanced Service (DES). PCTs had to improve the collection of data about the use of services by people with learning disability, commission regular health checks from by General Practitioners (GPs) alongside training for those GPs in communication and engagement with people with learning disabilities (NHS Primary Care Contracting, 2009).

**Why Annual Health Checks?**

There was already good evidence that regular health checks could improve health (Signposts for Success: NHS Executive, 1998, Romeo et al 2009). It has been shown that structured health checks identify more clinically significant health needs than opportunistic consultations (Cooper et al, 2006; Baxter et al. 2006). Regular re-checks are the are vital element for picking up morbidity and for health promotion (Felce et al 2008). Perry et al (2008) had identified that whilst people might have a health check, uptake rates were extremely variable. This is a key reason why annual health checks (AHCs) formed a key tenet of the policy for improving the health of people with learning disabilities.

The Lawnmowers Independent Theatre Company (ITC) was established in 1986 as a learning disabled led company. It pioneers creative and innovative strategies in order to help plan the lives of people with learning difficulties and provoke positive social change through developing long term, meaningful and cultural opportunities for members. At the heart of the company is its use Forum (ref) and Legislative (ref) Theatre to research, devise and create performances and workshops which reflect concerns raised by learning disabled people. The health of people with learning difficulties is a recurring issue that has been fore fronted in investigation and performance and members of The Lawnmowers ITC have done significant research and training in this area. At a recent meeting of 15 members of the Company we discussed Annual Health checks. Of the 15 people taking part in the discussion only 3 were aware of having had a health check that was designated as such. Other people had heard of them but were not sure what they were for and a number suggested that if they were invited they would be reluctant to attend as they were not keen on going to the doctors. This was despite the work the Company has done in relation to health and keeping healthy. If a group of relatively well informed and supported people are not taking up AHCs this goes some way to demonstrating the complexity of the issue.

From the 15 people who took part in the group discussion, four were keen to share their experiences of AHCs for this paper. The reasons they gave for doing this were so that more people might know about the importance of AHCs, but also that because there are still difficulties in accessing AHCs they want to help more people to take up the opportunity. They want to say what these difficulties are, not because they want to be negative about them, but it is Lawnmowers policy to be honest about their lives and make issues public. Letting people know that there are difficulties, making these public, can raise the awareness of the issues and help sort them out. Members of Lawnmowers ITC think the UK has some good ideas for supporting peoples’ health but the way these are rolled out needs to be improved.

**Personal Experiences**

Matthew, a young man aged 22 who lives independently from his family in accommodation he shares with others. He has recently had an AHC and was very positive about his experience. He knew why he was going for an AHC, that he had to go regularly, and that it would help you when you got older

*The last annual health check I went to was a few months ago I think. They do them to check my height, my blood pressure, my weight and things like that and to see if you are healthy. It’s like a check-up really. Annual means you do it all the time and stuff. Every now and then. They ask you to come in and stuff. They give you a text message or a letter or sometimes they call me to remind me. I don’t know when I go in next….I think they are excellent. Because when you are older…like fifty or something, you will be worried about your blood pressure and stuff. They will check to see if you are healthy and stuff and if you are not they will help to make you better… If you don’t have a check how do you know if you are ok? You might die or something.*

Matthew was not worried or anxious about AHCs. He recognised the need for them. He was also not worried because he recognised that he had the right kind of support. He really appreciated going with his mam as she can do some ‘translation’ for him when it is needed.

*Sometimes they ask personal things but my mam is there so they can talk in front of me about it. They tell her and then she talks to me about it. Doctor to mam, mam to me. So I understand.*

Matthew hopes that as he gets older, and learns more, he might be able to go for an AHC on his own, but does not think he is ready yet.

*I think I could go to a health check on my own one day. It would be hard at first to know what they mean but I might get used to it.*

Matthew knows a lot of his friends did not go for AHCs. Although he was concerned that his friends either did not understand about AHCs or perhaps did not have the support to go, he was also concerned about the doctors who were there to help people. Matthew sees AHCs as a vital part of maintaining good health and is positive about his local GP surgery. He believes that not going for as AHC is

*…..unkind to the doctors because they need people coming in and they want to check how they are doing.*

Matthew’s key message to readers is that AHCs are a very good thing. He wants to emphasise however that people need support when they are attending so that they can feel reassured, know they are safe and know they have properly understood what has gone on during the AHC and its outcomes.

Andrew, aged 36 lives with his mum and dad. He, like Matthew, is very knowledgeable about AHCs. He was part of discussions about AHCs that occurred between the University (Tina Cook) and Lawnmowers in 2009 and was an actor in the video Lawnmowers made to help people think about AHCs (http://vimeo.com/105745681?email\_id=Y2xpcF90cmFuc2NvZGVkfGZjYTQ4YWFlMWIwNmNmMmM2YmI5MWJlZDBkMjExMmY2MTY3fDI4MjgwNjIzfDE0MTAzNDY2NTV8NzcwMQ%3D%3D&utm\_campaign=7701&utm\_medium=clip-transcode\_complete-finished-20120100&utm\_source=email). This is what Andrew says about AHCs.

*An Annual Health Check stands for something you have yearly and it’s a check up to see if you are healthy… When I went for my last health check, I went in with my mam. They asked things about my diet, things that I drank. They took my blood pressure and monitored my heart. They took my reflexes with the thing that they whack off your knee. That’s what they did. Afterwards they just said I was in a healthy condition and I didn’t need to worry. They said I would come back again for another check but I never did. It felt really strange being in the doctors for things like that. Usually you go to the doctors when you are ill. I thought ‘Why do I need to have all of this done?’ ‘Are they going to turn around and say I am ill?’ But then in the end I kind of understood that it is a good thing to have it. It’s to make sure that you are keeping healthy and that you are not just going to fall down dead or anything.*

Andrew raises the doubts that other people with learning disability have about AHCs, why should you go when you are not ill and will the outcome be that they tell you are not well after all. Having had one, and come out of it still healthy, Andrew is positive about AHCs but interestingly, despite his knowledge of them, and the support he receives from his mam, he has not had an AHC since, by his reckoning, 1994.

 *I think they are important things that aren’t happening quite as good as they should. The last annual health check I had would have been in 1994. I don’t know why I haven’t had any more. We just don’t hear about them. We have never had any letters or phone calls about having them. My mam and dad know of them and know that we should have them but we don’t tend to get them. I’ve never gone to the doctors to ask about them because they are supposed to say it to you. I’ve been in the doctors for other health problems and they have never said I was due a health check.*

So, despite being aware of AHCs, the exact meaning of annual, the reasons for having them and having the appropriate support to attend, because Andrew has not had an invite he has not had one. This certainly raises the issue of responsibility on behalf of GPs to be proactive in inviting people like Andrew, because if Andrew did get invited, he would want to go and he knows his mam would go with him. This later point reinforces what Matthew said about not wanting to go on his own.

*If I got asked to go in for an annual health check I would never go in on my own. I always go with my mam. I don’t like going into places on my own like that. I find it hard to talk to the doctors. I would just clam up and not say the right thing. I don’t like talking to other people about my health without support. I think I would feel much more comfortable having an annual health check in a neutral place… like my house or in my living room. I would feel much happier about it all and less anxious about what the health checks are about.*

Andrew, like Matthew, sees AHCs as a very good thing but he wants to raise two important points that, if addressed, might mean that more people with learning disability get to have regular health checks. Firstly, that GPs still need to get better at inviting people to go for AHCs. Despite thinking that AHCs are important Andrew is waiting for a letter or notification from the doctor before he will attend. Many of the other people at the meeting also saw it as the responsibility of the health sector to ensure people are aware of overdue health checks. They did not want to bother the doctor by asking for one. Secondly, Andrew thinks that GPs need to recognise that people might be very anxious about going to the doctors because going to the doctors tends to be linked with not being well. Going to the doctors can raise your anxiety level “even when you know you are not ill, you worry that the doctor will decide you are”. People in the wider group discussing AHCs reiterated Andrew’s concerns when they spoke of their anxious feelings towards AHCs. They were confused by the prospect of visiting a surgery when they were feeling ‘well’ .. Andrew wondered whether, given that being in a GP surgery suggests that there might be something wrong with you, if an AHC could be done in a neutral place, where people felt more comfortable.

Graeme is 24 years old and lives with his mam. He has had an AHC more recently than Andrew. He agreed with Andrew that going for an AHC could make you anxious, especially if you were worried that the GP might be going to do some things you might consider personal

*They ask you personal questions about lumps in your areas and aww no it’s too personal.* ..[Graeme paused here - he did not want to elaborate further]

He went on to say:

*They normally ask you if you drink and smoke too. Mind you when I had my blood sample I went yellow because I tend to blur as I can’t see anything. I always get a side effect like that.*

But despite this issue with giving blood, like Andrew, Graeme knows AHCs are a good thing and he does attend

*You get your height done, your weight checked and a nasty bloody sample. It’s just a check-up once a year and I go every year with my mam.*

His message is that people need to know more about AHCs and go for them, even though it might be embarrassing or a little uncomfortable, because it’s important for leading health lives.

Debbie, aged 51, lives independently in the community with her husband. She does not have the support of parents to accompany her to the doctors. She too thinks AHCs are a good thing, and understands that they can pick up things that you would not know about without the help of various tests.

*I think everyone should get an annual health check. You could be at risk for many things. You could look healthy on the outside but there could be stuff going on inside. You might think ‘I’m fine, I don’t need it.’ Then they take your blood pressure and it might be sky high.*

She too raises the point that not everyone is aware of them.

*They are supposed to be where you get your health checked every year but not everyone knows about it ….unless the doctor tells you.*

Her story below comes from a time when she was not aware of AHCs and their purpose and demonstrates how confusing going to the doctors can be when you general health is conflated with specific health needs. She was given her AHC when she went to the doctors about a specific health need.

*I found out about these checks when I went into the doctors for something else. The doctor said to me, ‘Oh by the way because you have learning disabilities you are entitled to a health check?’ I didn’t understand what it was for. It was a bit annoying. I thought it was to test my capabilities not blood tests and things like that. I got weighed, had my height taken, blood pressure. Didn’t hear anything back about it…everything is fine I think!*

Debbie had not had a diagnosis of learning disability at this point, despite being an adult and having difficulties all her life with learning. She feels this has had and adverse effect on her life and her ability to get the support she needs to live independently. There are a number of very difficult things that have happened in her life that she feels would have been different if she had received a diagnosis of learning difficulty and been given some help. She had thought the health check she was being given was part of ascertaining her learning difficulty and had been anxious when she did not hear anything back after having it done. Debbie now has a diagnosis of learning disability, which she finds helpful, but reflecting on whether she has had further AHCs she realised she was not sure.

*I haven’t had a health check for ages. I can’t remember the last time really. I don’t get any letters or anything. It’s a bit confusing because when I go to the doctors they take your weight and blood pressure anyway. Is this an annual health check? Or you would think when you go to the doctors that they would say you are due another one?*

She too raises the point that it would help if GPs wrote to them about the AHC then she would know when to go and whether she had had one or not. To just do it as part of you being at the surgery for something else can be confusing as sometimes when you go for an illness you need your blood testing anyway. She is unsure whether she has, therefore, had a full health check.

*Sometimes I worry that I haven’t had an annual health check. It’s annoying because one minute they say I am entitled to an annual health check because I have disabilities and then the next minute I hear nothing.*

The need for support to both attend and be confident during that process was discussed by members of the group and Debbie’s story of being someone who has had had to navigate this on her own demonstrates that confusion abounds. What became clear was the importance of support from family members and key workers to help make something like the annual health check are more positive and accessible experience. Debbie’s message is that GPs could help if they did not muddle AHCs in with other aspects of health care and assessment. If they invited her for an AHC specifically, she would know what it was and why she was going. Being confused and a little annoyed is not a good basis for health. Andrew’s suggestion of having the AHC somewhere neutral that was associated with health rather than illness, might also be helpful in considering how to clarify the difference between being ill and staying healthy, and make people more comfortable about attending.

People in the wider group discussion were clear that if they could understand what was going on they would be better able to act appropriately. Not understanding makes you anxious and so you are less likely to want to go for an AHC. In addition to not knowing quite what an AHCs might look like, the wider group also discussed the use of terminology, the words doctors use. They described experiences of going to the doctors or the hospital and finding themselves in an inaccessible world of medical jargon. This had left them feeling confused and bewildered. They were not keen to voluntarily put themselves in such a position again. For some the word annual was part of that problem and led to confusion. Some thought it might mean ‘…every now and then’ or ‘…when the doctor gets in touch.’ It was suggested by Andrew that if AHCs had been called ‘yearly’ health checks that would have helped

Considering the health inequalities faced by people with learning disabilities it is critically important that healthcare services in England address access issues to what could support their general health needs. Since 2008 a number of things have happened in the UK to begin to address the issues highlighted in the Michael Report but change has been slow given both the size and the embedded cultural nature of the issue. In 2010 Emmerson and Baines summarised the available UK research literature concerning the health status and needs of children and adults with learning disabilities reiterating that health inequalities faced by people with learning disabilities in the UK result, to an extent, “from barriers they face in accessing timely, appropriate and effective health care” (Emmerson and Baines 2010:1). Writing again in 2011 Emmerson et al state “It is clear that these health inequalities are, to an extent, avoidable. It is also clear that existing patterns of healthcare provision are insufficient, inequitable and likely to be in contravention of legal requirements under the Equality Act 2010, the Mental Capacity Act 2005, the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and 2005 and the UN Convention on the Rights of Persons with Disabilities” (2011:18 ).

The issues raised by members of The Lawnmowers ITC about accessing AHCs are very pertinent. In 2010 Dr Matt Hoghton and the Royal College of General Practitioners published a document entitled ‘A Step by Step Guide for GP Practices:

Annual Health Checks for People with a Learning Disability. This provides information, advice and guidance to help General Practitioners, Practice Nurses and other staff at surgeries to support the process of AHCs with people with learning disability. It provides a clear protocol for developing knowledge of people with learning disability in the practice catchment area and supporting their attendance at AHCs such as

* Invite patient for a health check (using appropriate method and accessible information)
* It is also recommended that practices attach the pre-health check questionnaire (available from www.rcgp.org) to help prepare the patient and carer for their health check appointment, reduce anxiety and improve effectiveness of appointment. Check that this invitation has been received.
* Offer choice and try to make the appointment at a time and day of the week convenient to the person and their carers as well as to the practice (2010: 8).

It also provides proforma for letters inviting people for AHCs in an accessible manner. Almost all the issues raised by the members of The Lawnmowers ITC in relation to AHCs are covered in this comprehensive document. Some GPs such as Martin and Lindsay, had hopes that this enhancement of services in the form of AHCs would improve the health of people with learning difficulties

“It is possible that this vulnerable group of patients, who have difficulties accessing health care, could enjoy better health with early diagnosis of several remediable conditions, including some cancers, if the new DES is effectively implemented by GPs”. ( Martin and Lindsay, 2009: 481)

The experience of this group of people from Lawnmowers is that, despite all the support for GPs to make this work, there is, for still a gap between policy, guidance and its application.

Matthew, Andrew, Graeme and Debbie all think that AHCs for people with learning disability are a good thing and have the potential to keep people healthy because there are illnesses that you don’t know you have, and having those found during an AHC can mean they can be treated and you can live healthily for longer. Members of The Lawnmowers ITC are researchers, thinkers and actors in relation to the inequalities faced by people with learning disabilities. As access to AHCs, something they see as a good thing, remains difficult for them they hope that the articulation of their experiences might help address some of the difficulties and support other people with learning difficulties in gaining access to health. They know that being unhealthy can lead to great unhappiness: most of them have have either personal or close experience of that. Being happy and healthy is really important to The Lawnmowers ITC and to their friends and families. They would like to help make AHCs work.

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1. The term learning disability and learning difficulty are often used interchangeably in practice and so in this paper. There is no diagnostic difference, and learning difficulty tends to be the term preferred by the members Lawnmowers Independent Theatre Company. Learning Disability is more often used in health situations. [↑](#footnote-ref-1)
2. Primary care trusts (PCTs) were part of the NHS in England. They were largely administrative bodies responsible for commissioning primary, community and secondary health services from providers. PCTs have since been replaced by clinical commissioning groups (CCGs) [↑](#footnote-ref-2)