



What do we think? Feedback on the White Paper Equity and Excellence: Liberating the NHS

Name



Inclusion North is submitting this regional response on behalf of its member areas.

Inclusion North works in Yorkshire, Humber and the North East to promote inclusion for people with learning disabilities, their families and carers.

Inclusion North CiC is a not for profit membership organisation.

Members used the questions set out within the easyread version of the White Paper Executive Summary. In addition, 3 other more general questions were asked to ensure that people with a learning disability could engage and respond to this consultation.

Organisation Type

11 different groups have returned local information that has informed this regional response:

5 Learning Disability Partnership Boards:

- Kirklees
- Sheffield
- Hambleton & Richmondshire (North Yorkshire)
- Bradford
- Hartlepool

1 Partnership Board health sub-group:

- Rotherham

5 learning disability self advocacy groups:

- Sunderland People First
- Living Our Lives, North East Lincs
- Eleveses Group, North Tyneside
- Middlesbrough People First
- Stockton Helps All

1 voluntary sector organisation:

- Learning Disabilities Federation, North Tyneside



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How should the NHS decide on the most important things to work on?

- Make sure that joint working between NHS and Local Authorities continues.
- In order to address the major concern that people with learning disabilities will be forgotten:
 - GP consortia must be forced to consider the needs of people with learning disability and their family carers (mandatory monitoring).
 - There needs to be an organisation that monitors how the health of people with learning disabilities is managed.
 - Learning disability needs to be considered as a “specialist service” to ensure there is expertise available to GPs.
 - Look at the outcomes and the work on the Health Self Assessment Framework in each region to make sure there is good progress on “Six Lives”/”Death by Indifference”. The local performance needs to be scrutinised to assess if there is good progress.
 - Need to know how many people there are in each city with a learning disability and how much money is spent.
- Focus on care and quality
- Consult people who use services and family carers in a way that is appropriate to them.
- There have been a range of solutions used in recent years that have led to people with a learning disability achieving improved health outcomes, such as annual health checks, accessible health action plans and easy read information. People do not want these solutions to lose momentum.
- Need clear local information about what local choices there are.
- Employ self advocates to check local performance
- There needs to be more training and awareness of learning disability in the NHS generally. It is worrying that GP’s who will have most say in how money will be spent get very little training in learning disabilities.



How can health and social care services work better together to help people be healthier?

- Joint planning needs to continue across Local Authority and NHS using Valuing People Now and underpinned by “Six Lives” – good communication.
- Use “hospital passports” to make sure the needs of people are understood across the system.
- Making sure notes are passed on with people properly
- “Health and Wellbeing Boards” need to ensure they maintain a focus on learning disability as an equal priority to cancer, mental health, older people etc.
- Making links with social services when people have been treated by health services to make sure they receive the support they need afterwards
- Making sure there is better communication between health and social care partners
- People are concerned that funding from PCT’s and Local Authorities to the voluntary sector will be lost, as grants are terminating and whether GP consortia groups will recognise the early intervention and prevention work
- Support and make use of the local Partnership Boards (which include health and social care partners) to find out about issues and their ideas for resolving these.
- Support and encourage the use of self advocacy support to enable people to speak up and casework advocacy to support people to resolve issues.
- Talk to people who use services about the barriers they encounter when using different parts of the health service.
- Check the quality of direct support services to ensure the staff are providing person centred services.
- Improve the range of flexible support available to people so it meets their needs on that occasion.

How could local doctors and social services work better together to make sure there are the right services?

- Annual health events on learning disability.
- They need to know and understand more about the health needs of people with learning disability.



- They need to be brought up to date on issues relevant to learning disability (doctors need to learn from Local Authority Social Care).
- There needs to be a relationship between the Health and Wellbeing Board/GP Consortia/Specialist Commissioning Board and the Learning Disability Partnership Board.
- “No decision about me without me” needs to apply as a planning principle too.
- GPs would need to have more time.
- There should be more services to stop people with mental health problems becoming ill.
- Access to other support services eg. counselling and other services.
- Social services need to listen more to people with learning disabilities and their carers when they are planning services.
- Address assessment barriers and create a pathway to enhance service provision.
- Give clarity over how the transition will be managed and how the proposals will strengthen the community sector, those specifically working with people with disabilities or long term conditions
- More awareness needed of the local provider market
- Look at assessment forms – make them more about outcomes focussed.
- Make use of existing information about people’s health needs
- We need to make sure that the existing information and important work carries on, as the NHS and commissioning change.



To make services better local doctors and the new NHS board need to involve local people. What is the best way to do this?

- Audit and identify areas for improvement.
- Present information in a way that is understood.
- Reach out to representative groups

- Clear agendas – quicker planning and actioning.
- Consultations – should consider the audience, to prevent information overload and use realistic time frames.
- Talk with the Learning Disability Partnership Boards.
- Family carer reps and people with a learning disability should be on the Boards and patient forum.
- Need GPs involved in Learning Disability Partnership Boards.
- Need to find out how people feel about health and social services and use this information when deciding what services to buy.
- Informal groups/forums with GPs.
- Making sure views of all groups (BME communities, people with learning disabilities, professional carers, family carers) are gathered
- Information needs to be accessible. The NHS needs to make sure it reaches all groups – including those who are seldom heard.
- Advocates know people well and are skilled at supporting people with a learning disability in a range of settings. They know how to communicate with people.



HealthWatch is the new group who will speak up for patients. How can they work with local people to make sure the things people say are heard?

- They must ask all services how they meet the needs of people with learning disabilities.
- Local learning disabled people and their carers must be involved in local HealthWatch.
- The Expert Patient Programme should be a foundation.
- Must think about accessible communication.
- Strengthen patient advocacy.
- Ensure we influence the Health and Wellbeing Board.
- Can we strengthen Community Assemblies?
- Need to use existing organisations that are skilled at involving people who find it hard to speak for themselves (share knowledge and experience).
- How do we ensure local voices are heard – especially the most disenfranchised or least able to communicate easily.

- Need to link with relevant groups and also NHS Foundation Trust governors.
- Must focus on all areas of health, not just areas that its members have an interest in.
- Newsletters, forums
- Quality checks by self advocates/service users.
- Monitoring by the Care Quality Commission
- Work with other organisations and services.
- Flexibility in reaching people.
- Surveys and questionnaires in an accessible format.
- Meetings – link into other groups to highlight similar issues- local Partnership Boards and also those that focus on regional needs.
- There is concern about the change to HealthWatch groups in areas where there has been great progress with LINKs and the impact this change will have on its scrutiny function.



What can we do to make sure that these new plans treat everyone fairly?

- NHS needs to think about how using “confidentiality” can be a barrier to working jointly across health and other organisations eg. social care/third sector organisations.
- Identify which groups we need to engage with.
- Genuine involvement is key.
- Equality Impact Assessments need to be used properly.
- Use the Health and Wellbeing Board and learn from other groups.
- How do we ensure consistency across GP consortia?
- How will GPs listen to:
 - People with learning disability who are not very vocal or visible?
 - People who are not using GP practices?
- Representation on commissioning boards or associated meetings should be proportional to people using services/carers.
- Identify who is in the local community – youth, older people, general public, ethnic minorities, learning disabilities and mental health, profound needs, carers, self

advocates, advocacy support. Liaising with bordering services to provide the care need.

- Feed information out – communication networks – regularly and clearly.
- Patients must be listened to properly and given the time they need.
- Information should be available in a way patients understand and for people with a learning disability this is easy read leaflets and papers for consultations.
- Learn from the success of existing LINKS



Healthcare comes from different organisations. How can we make sure they all have the same chances to get work?

- Ensure the third sector is encouraged and supported and can offer services.
- Different organisations need to meet at Partnership Boards.
- Organisations need to listen to patients/service users.
- People with learning disabilities, mental health difficulties or other illnesses should be part of Health Watch.
- People need to know where to go for help.
- It would be helpful for some people to have something more informal in local areas, eg. “drop-in” sessions
- GPs could work with community assemblies.
- Links between services, for example, like neurological and mental health for people on the autistic spectrum – this should be more joined up.
- We want to encourage smaller health providers, but they must also be of a high standard.
- Involve patients in the process.
- Work in partnership
- Create regional links to promote good practice
- Develop ways for providers to work together
- Create a flexible approach to service budgets and structure to allow private and voluntary sector care to be bought in.

- Need to ensure that local Joint Strategic Needs Assessment and local intelligence is not lost in the transfer



What we think about the big ideas that are in the White Paper and if these are the things that matter to people with a learning disability and family carers

- We welcome the Government's commitment to the values of the NHS: a comprehensive service free at the point of use, based on clinical need and available to all.
- We also welcome the emphasis on reducing health inequalities.
- People not too bothered about seeing the same GP each time as long as they have the right information about you and provide a good service.
- If IT records continue to improve, this will help to make things happen.
- People want the good things to stay good. This includes James Cook Hospital in Middlesbrough. They already let staff stay overnight when needed and the hospital staff are supportive of the work that advocates do.
- Some people felt that it was particularly good to have:
 - HealthWatch England
 - Care that is right for them and their carers
- In some areas of the White Paper, there wasn't enough detail for people to assess how the proposals would work, for example:
 - making people's health better
 - sharing of information
- People also felt that there were lots of changes proposed within the White Paper and very limited time available for people with a learning disability and their supporters to engage fully in this process.
- There needs to be more information provided about how the proposed changes will be implemented.

- How do the proposals for GP consortia affect areas whose LA boundaries represent less than 100,000 people?
- Will public health funding be ring fenced?
- There were concerns raised in respect of Patient safety, safeguarding and adult protection.
- Deaf Citizens of Hartlepool raised concerns in respect of the PCT contract via GP surgeries and the interpretation service, hoping this would improve if GP consortia groups commissioned services by locality.
- People accessing preventative mental health services asked how these services would be funded when PCT & SHA disappeared with issues of equity and equality.
- Carers raised concern in respect of services that are Joint funded (LA & PCT) and how these services may disappear.



What we think is good about what this White Paper says

- The principles set out are good, especially more effective use of resources that improves the quality of services.
- More flexibility and control over your choice of service:
 - Patients “voice”
 - Clear choices to choose my care from
 - Services being open and honest
 - Support in voicing views, with HealthWatch England
 - Personalised services eg. Medication
- Rhetoric is good at putting people first. “Strengthening the voice” is good if it comes to reality.
- The savage funding cuts in public services give the rhetoric less chance of being a reality.
- It is a chance to look at services again.
- We need to make sure that improvements that have been made in the NHS continue and are not lost.
- “No decisions about me without me” is important.
- It is good to have more information to make choices.
- More control over things that are written down.
- More choice about people who help them look after their health.

- Prevention and support in the community is less expensive and better for some people than going into hospital.
- Forces better joint commissioning, could lead to a more preventative approach.
- Combine professionals and users in decision making about the NHS.
- Strength of the “patient voice” (providing they listen and hear the voice of people with learning disabilities).
- Use of pathways could improve, providing people with learning disabilities are on pathways.
- Public Health may have stronger links with the local authority and can combine its resources locally
- Some GP’s have good working practices and surgeries are accessible making it easier to access.
- Some of the funding will be put to use in front line services



What we think is bad about what this White Paper says

- The timescale of change is very fast and the details on how it will be done are not clear.
- The speed of consultation is very fast and has not given people enough time to fully understand the big changes.
- People with a learning disability need much more time to engage meaningfully in a process of consultation of this scale.
- It has come out too quickly and as a result there are significant concerns about the scale and speed of such profound restructuring of the NHS
- It makes people anxious because of the scale of the change and the “leap into the unknown”.
- There has been hard fought progress on learning disabilities and improving the health of this group. There are concerns that the new structures will be less informed (GPs do not have the knowledge, expertise and commitment to ensure the learning disabled people’s needs will be met).
- How much do GPs know about the needs of people with a learning disability?

- Will there be perverse incentives to marginalise people with most complex needs who are the “most expensive”?
- Not yet clear how Public Health will be included – risk of a separate process.
- There is concern at the scale of financial costs unavoidably associated with such enormous restructuring, particularly at a time when health organisations, like other public sector bodies, are required to scrutinise costs so stringently
- There will be organisational costs - low morale, loss of expertise and loss of organisational memory through early retirement and voluntary redundancy – which we are already seeing and experience tells us will increasingly arise from reorganisation
- Financial expenditure of this magnitude is attached to a process that lacks an evidence base
- There could be a potential loss of high quality services plus skills and expertise embedded within them, as a result of structural change, and the impact that this will have on both vulnerable groups and the wider community
- The lack of defined responsibilities for the health of geographically-defined populations could negatively impact on vulnerable groups, such as people with a learning disability.
- With the proposed demise of a regional architecture there is grave concern that these groups will lose their advocates to shape the development of both local consortia and the work of the NHS Commissioning Board. Locally, the vagueness of the proposals concerning internal governance requirements of local consortia is significant – we see little evidence of an understanding or a willingness of local primary care consortia to engage with, sustain and develop the voice and influence of people with a learning disability. Further work is needed to determine what forms of support and networking will exist for those working with small population groups once

regional bodies cease to exist, so that their voices can be heard.

- We feel that the 'choice' agenda disadvantages the vulnerable in society who can be both unaware of and unable to access care or services they need.



Anything else?

- It is good that there has been an easy read version; however this was published much later than the majority of the other White Paper materials. People with a learning disability need more, not less time to engage in a consultation process of this scale.
- The consultation deadline is not clear. On the website it highlights 11th October as the deadline. When you go into the full Equity and Excellence White Paper itself, it states 5 October. There is no date given on the Easy Read version – this is very confusing.
- Lots will change very fast. We need to make sure that the time that the NHS has spent learning about how to give good care to people with learning disabilities is not wasted.
- What will happen to the people in some of the existing specialist posts who do good work now? This includes Health Facilitators, LD psychiatry, LD nursing. They do things like supporting people when they present challenging behaviour and mean more people have a Health Action Plan and better health as a result.
- What will happen to make things better for people with complex needs? Will the new or different ways of working have the time and skills to work well with these people and their carers?
- How will GP's ask people what they want services to look like? Sometime they don't do this now because they don't have the time so not sure how this will work in practice.

- What will happen to advocacy services – how will they be funded? As money moves to GP's and people get personal budgets how will these services be bought?