

Green Paper 'No Voice Unheard, No Right Ignored – a consultation for people with learning disabilities, autism and mental health conditions – Department of Health, March 2015

***LONDON ADASS RESPONSE TO THE
DEPARTMENT OF HEALTH
CONSULTATION ON THE GREEN PAPER
NO VOICE UNHEARD NO RIGHT
IGNORED***

1. Introduction

1.1 Overview

The London branch of ADASS welcomes the opportunity to respond to the consultation on the Green Paper: No Voice Unheard, No Right Ignored.

It was agreed at the jointly chaired learning disability commissioner network (ADASS and NHS England) to discuss and submit a joint response from the London region in addition to any individual responses that areas may individually make. The paper has been considered by local authority and health commissioners in the five sub regions in the London area and comments were also requested from Directors of Adult Social Services in London. Responses were received both in writing and at sub regional consultation meetings held in April and May 2015. A pan London meeting was held by LSCP on May 20th to review feedback from the sub regions and agree the London response. The meeting was attended by 24 representatives from local authorities, CCG's and NHSE (London). The full details of all the feedback and comments are included in this report and we have also provided a summary of the key themes that emerged from all the consultation feedback below.

1.2 Summary of views on the consultation:

- There is no need for new legislation – there is enough already; what is required is the strengthening of existing law.
- The use of independent advocates to support people through the mental health system and ensuring people understand their rights etc. is patchy and needs improving.
- The focus on promoting independence and rights is welcome as, although there is already an emphasis on this, it has not necessarily changed practice.
- Some of the suggestions regarding the Mental Health Act feel unnecessary after a massive CoP consultation and in view of potential changes to DoLs and MCA once the Law Commission has completed work in these areas.
- It is essential that proposals with new costs are fully funded
- Any proposals on staying closer to home need to take account of the geographical circumstances in London and space restrictions

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2. Specific Answers and Comments on the Green Paper

2.1 Section 1: My right to be independent, to be part of a community and to live in a home I have chosen

Q1 The Care Act says that local authorities have to put individuals' wellbeing at the heart of what they do. We want to explore whether NHS commissioners should have the same duties, for example, for people with learning disability or autism who are at high risk of long stays in hospital in relation to their lifelong needs. What do you think of this idea?

Care Act duties are clear for local authorities. It would be useful to have additional duties for Health commissioners for LD clients.

However current NHS duties need clearer understanding and the same commitment to life outcomes and wellbeing for individuals the NHS works with. These duties may be covered in other systems, for example health equality frameworks. It would be beneficial for families to see the requirement for positive outcomes at the heart of commissioning.

The Department should consider how the JSNA process can be more robust for people with learning disabilities (PWLD) and Autism and that it should have clear links with the self-assessment criteria.

The Department needs to consider the possible negative impact of the transfer of responsibilities from PCT's to LA's and whether this has weakened health duties. It should be recognised that health and local authority commissioners will have different priorities; stronger national definitions of LD would assist. Strong self-directed advocacy for the individual would support any new well-being duties.

It is not clear how CCG's will fund any new proposals.

Q2 In making decisions on living arrangements (whether suitable accommodation or inpatient stays) both LA and NHS commissioner should have regard for factors which support inclusion in the community. This could include staying close to home, links with family and friends, opportunities for participation and least restriction. What do you think of this idea?

Clearer guidance on suitability of living arrangements would be welcomed as crucial to positive outcomes. The wording in the could be stronger: 'should include staying close to home' rather than 'could include'. Definition of 'least restrictive' is needed; wherever possible would expect a setting that is not restricted and when it is restricted, this is as minimal as possible.

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Guidance should include when regional / out of borough placements are acceptable; for example should a key criteria be accessibility / travel time and opportunities to use new technology to link families? This is particularly relevant in London where the geographical area may be smaller and choice of home may be in a different borough particularly given restrictions of space in London.

Availability of local resources needs to be considered and role of private providers but this proposal should make the need to develop local services more apparent. However, any guidance should not be overly prescriptive and should give local areas some flexibility. More regional working and joint funding of individuals should be encouraged particularly where CCGs / Las are commissioning for low incidence high cost services. There should be an expectation and possibly requirement to collaborate with other CCG's /LA's . Priorities for Health commissioners and Social Care commissioners do differ and guidance/legislation should encourage closer alignment.

LA's are aiming to keep people in the local community, using S75 agreements with CCG's to operate community services. However there needs to be more trust between commissioners and social care staff. The Department should look to strengthening existing duties on neighbouring / regional CCGs to work collaboratively.

The Department is asked to consider housing and housing benefit legislation and practice to avoid loss of tenancy when PWLD or Autism are admitted to hospital.

Q3 If so, what might the appropriate length of inpatient stay be where this should apply to the NHS?

There are concerns about setting timescales and length of inpatient stay as targets may drive care and length of stay should be related to individual needs. It would be preferable to establish a specific care pathway following admittance. Care and treatment reviews should be embedded in admittance procedures, consistency and guidance is needed.

The care pathway needs to evidence that the person is receiving assessment and treatment throughout the stay. Discharge pathway needs to be unique to each person (and part of the admission process).

Q4 What are your views on how this might impact on LAs and the NHS?

The proposal could run contrary to a person centred, individualised approach. It would be preferable to establish a care pathway and agree a discharge plan and date on admission. We recommend there is a formal mechanism to monitor this process; however, this will have a resource implication for LA's and the NHS. The Department should consider how it can support commissioners to establish appropriate contract levers such as financial penalties or incentives. This should be

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accompanied by a set of national performance indicators (for example, Commissioning for Quality and Innovation).

Q5 We think that local authorities and the NHS could have to think about how to ensure enough community based support and treatment services (for example, for people with learning disability or autism most at risk of going into hospital). What do you think of this idea?

This is supported and is a key priority for LAs and CCGs. Wording should be stronger – ‘should’ have to think about rather than ‘could’. The Department should consider how more support for family and carers could be provided which would decrease the need for direct services; this should include adaptations to homes.

Consideration should be given to the pace of change particularly where bed closures take place without sufficient community resources and the need to keep in mind provider failure and sustainability of services as beds close. We would welcome the views of the Department on developing strategic plans/risk sharing protocols with providers, commissioners and NHSE.

Need to acknowledge that the drive for market development may need joint funding to develop new services and better systems for establishing if primary needs are mental health or learning disability.

In addition the JSNA should include risk profiling of PWLD and Autism most likely to go to hospital. This should include formalising a requirement for an ‘all age’ commissioning plan in local areas.

The outcome of the consultation should be considered in the light of the NICE guidelines on challenging behaviour and learning disabilities, due to be published in May 2015.

Q6 What steps could we take to ensure such a duty is as effective as possible?

Health and Social Care should be working closer together, for example through joint commissioning and through pooled budgets, could consider strengthening of duties on CCGs to cooperate such as the NHS CCG code of governance – principle 3. Could be a requirement for all LAs / NHS commissioners to report on such placements and how they plan to meet that gap in the local market. Also, possibly have an annual report to Health and Wellbeing Boards.

There is a need to strengthen behavioural support available for people living in the community to prevent/lessen likelihood of admission.

Q7 What is your view on the likely costs or impact of such a duty on the NHS? Local Authorities?

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The Green Paper refers to 'Fully funding commitments'; there will be a need for pump priming in new community services before funding can be disinvested. Transition can take up to 6 months from an in-patient setting and funding commitments will need to reflect this.

The proposal is not savings driven and would improve people's quality of life.

However, there is evidence in London that behaviour management specialist teams save costs in the system by working to prevent admission.

Impacts will be on developing new approaches to risk sharing, particularly regarding high-cost placements and increased investment in community services. There is a need for more commissioning support and innovation as the current market is heavily influenced by providers.

It is essential that the quality of health information available through primary health care systems is improved. Primary care professionals/GPs need more training and support from community services in working with PWLD and Autism who have higher needs.

More sharing of good practice would be welcomed and lessons from the reconfiguration task force and Integrated Personal Commissioning pilots.

Q8-Q9 Assessment and treatment in the community and the Mental Health Act – see attached information 1.23-1.28

Q8 What do you think about the idea to change the information which is required by Mental Health Act regulations applications for detention and supporting medical recommendations. This would mean that Approved Mental Health Professionals and doctors have to consider and record whether assessment and treatment could be provided without detention in hospital.

It was felt that the current Mental Health legislation was sufficient as AMPHs are already required to consider 'least restrictive' option. AMHP also has duty to challenge doctors when they don't think decisions / process being properly followed. Focus should be more on making existing systems (eg MH tribunals) more robust. Placements often made because of behaviour issues, where assessment is not the issue. More important to ensure appropriate action is taken when it is required and is as proactive as possible (rather than just focussing on the section).

Could there be a new section for PWLD with time limits, different treatment pathways? Benefit would be to prevent endless admission; difference to length of stay for sex offenders compared to the criminal justice system - provide opportunity to evaluate risk of discharge and how can be best managed rather than actions that led to admission.

It was recognised that this proposal may be to clarify the wording of the MH Act – specifically the requirement to decide whether there is no other suitable alternative.

To ensure quality assurance it is perhaps more relevant to ensure that AHMP services have sufficient capacity and also relevant training and experience, eg. More

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focus on learning disability in training. RNLDs and other relevant practitioners with LD background should be encouraged or incentivised to undertake AMHP training. Local MHA offices do not record mental capacity application outcomes and it is suggested that the MHA office implement a new system. It is not always clear why a patient has been sectioned. Information that led to such a decision should follow the patient through their care pathway so that Tribunal panels, for example, have sight of them.

There would be commissioning benefits to tracking AMHP decisions and recommendations, to help increase knowledge of what provision is available in a locality and to help identify gaps in provision.

Q9 What is your view on the likely costs or impact of this idea?

More investment would be required to ensure implement this proposal and any change is likely to increase pressure on AMHP services and waiting lists.

Section 2. My right to be listened to and have my wishes acted upon. My right to challenge decisions about me.

Q10 Rights -see attached information 2.1- 2.11

Q10 We want to explore whether a person and their family/carer or other nominated person, should be given clear, easy read or accessible information by a named professional about their rights. What do you think of this idea?

Agree with the principle of easy to read accessible information, in various formats. Commissioners should monitor and consider the skills of professionals and how information is relayed to people in an individualised manner to support needs. The person's understanding of the process should be evidenced and recorded. The views and opinions of people already in the system should be obtained and used to quantify how well systems are currently working. Statutory agencies should have to justify and oversee the process to ensure individual rights are adhered to.

Q's 11-14 A right to challenge admissions – see attached information 2.12-2.13

Q11 What do you think of the idea that local authorities and NHS commissioners should have to seek explicit and documented approval or consent ³⁸ from an individual to admit them to an inpatient setting. This could include a record of discussion around options and risks.

This should happen already; as part of the Mental Health legislation and should be a standard procedure at the point of a MH section into an inpatient setting.

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People should be using the MCA to inform practice and where someone clearly has an ability to make their own decisions it should be routine practice to seek consent. If consent is given, would funding responsibility fall back to the LA? Having advance directives in place to address how the person wants to receive treatment when/ if they need it would be good practice.

Where this practice is not happening, should be embedded into the process of any new admission. There could be potential concerns in relation to occasions when the family or person do not agree with the admission into hospital under a MH section. The use of advocacy and exhausting best interest approaches should be explored in such situations.

It may be more difficult to implement this proposal in a crisis/emergency situation. Eg. If a person is in a state of mental distress, are they the right person to give consent (assuming they have capacity)? Proposal may also lead to unwieldy processes.

Q12 What do you think about the idea of a gateway or approval mechanism for admissions to inpatient settings, in certain circumstances?

This is seen as a positive way forward and should help to ensure that commissioners are doing everything they can and only using admission as a last option. The mechanisms are already there, need to ensure they are used appropriately. Need to clarify if the gatekeeping process is the AMHP or the NHS funding agreement.

A gateway similar to a brief care and treatment review could be convened to form part of the process of any new admission. This should lead to good practice and a transparent streamlined approach to share information with families, the individual concerned and all those involved.

In London there are some examples of services that provide preventative support to people on an outreach basis to avoid hospital admissions; would be good to extend this throughout the country. An intermediate specialist service could be developed for people in need of treatment as a way of reducing the number of admissions into an ATU.

Q13 What would be the essential elements of such an approval mechanism?

- Independence
- Lead decision maker
- Buy in and approval – but need to be aware that this will be limited in an emergency ‘Friday night’ placement?
- People knowing about mechanisms
- Checking assessments up to date, properly carried out, that all possible treatment options were considered.

Q14 If there were to be such a mechanism, should it be given statutory force?

The majority would agree with this principle. However, the answer to this would depend on the mechanism. – would need to know what this is first. Similar processes must already exist elsewhere. Don't want to create barriers to someone accessing treatment when in a crisis.

Qu's 15-17 A right to seek transfer or discharges – see attached information 2.14-2.20**Q15 What do you think of the idea of strengthening (for example in statutory guidance) people's rights to request a transfer to a less restrictive setting or a setting closer to home or to ask for a discharge?**

This was felt to be a good proposal and builds on the lessons learnt from Winterbourne to seek placements close or within funding areas. Already a clear pathway in place (tribunal to request discharge). Good quality independent advocacy needed to be available to question and represent people at tribunals – this is already enshrined in the Winterbourne Concordat. Change of culture needed e.g. professionals willingness to listen to advocates. Could the role of advocates be strengthened - their understanding of the Acts, their training and their ability not to just listen to that person, but speaking to family members and those close to them and challenging the professionals, not just accepting info given. This links to suggestion to strengthen training of IMCAs and appropriate qualification. Need to consider whether pay is too low. Also, appropriateness of advocates being funded and supplied by providers (e.g. POHWER services).

The initial care and treatment review prior to admission should ensure people are aware of the length of treatment and section conditions. A clear protocol/process would be needed when a right to seek transfer made so this does not become an automatic right to transfer.

Q16 Do you agree that, as far as practicable, such decisions and discussions should involve professionals or staff based in the community or expert on community based options?

As far as practically possible decisions should involve the person concerned supported by a combination of all those involved in the care and treatment process. Services should be driven by a needs led approach and not by options available. Local areas need to ensure that there are effective options available in the community. Could have community based professionals as part of the process; experts in services who are not tied in to placements would benefit the individual.

Q17 How can we strengthen provider and commissioner accountability in their approach to such requests?

In order to strengthen the protocol referred to in Q15, accountability should be measured against improved outcomes within placements and monitored.

This will lead to a stream lined approach across services and ensure accountability to promote good practice. Need to develop bespoke tailored services and consult with providers to deliver care in the community in accordance to individual needs.

This proposal may have resource implications under ordinary residency and the new Care Act.

Qu's 18-20 A right to early discharge planning – see attached information 2.21 – 2.24

Q18 We want to explore how everyone can receive care planning and discharge planning from the time when they are admitted to hospital. One way we could do this is through new statutory guidance (complementary to the Mental Health Act Code of Practice). What do you think of this idea?

We agree that realistic discharge planning should be planned from the time of any new admission and should include clearly planned outcomes for the stay. Pre discharge portfolios that are accessible need to be core to service delivery.

However, would go further to suggest that discharge planning could start prior to planned admissions with 'pre-planning' that could include contingency/support planning and could help minimise in-patient stays.

Not clear that statutory guidance is needed (see Q4) although a protocol/guidance from ADASS may be useful. There should be a way of ensuring reviews of care and support plans and making professionals accountable for delays in discharge. Delays in discharge could be monitored by organisations such as CQC who can reflect on trends within organisations. This would need agreed performance measures to be in place

Q19 Should we require a care plan, including a plan for discharge, to be produced involving individuals and their family within a specified number of weeks of admission and to specify when it will be reviewed?

Yes but reference Q3 answer. Need to refer to care pathway, be person centred, understand that pathway is changeable. Need open lines of communication that are transparent.

Q20 Could more be achieved through any existing policies or guidance on delayed discharge?

There is a need to improve the NHS standard contract. Failing or poor providers should and can be dealt with by commissioners.

Failings or poor practices should be reported to CQC and a record kept by CQC that can inform local areas of providers who have failed to remedy concerns.

Q21 - Challenging Mental Health Act admissions – see attached information 2.25-2.26

Q21 The Mental Health Act Code of Practice has just been updated. In line with this, we want to explore how people and their families can be more involved. One idea is that people and their families or advocates should be able to challenge whether an Approved Mental Health Professional has properly taken into account their wishes and feelings in the interview which takes place before they make an application for admission under the Mental Health Act. What do you think about this idea? (we would need to consult later on how the details of this process might work)

This depends on who would deal with the challenge and what powers the recipient of this challenge would have to investigate and redress the issues. If this was to form part of CQC compliance framework it could work, but capacity within the system to carry out this work is questionable and additional funding to support this could best be used elsewhere- such as advocacy proposals identified elsewhere in this consultation or family support and counselling.

This is good practice and should be happening anyway; there needs to be a recognition that AMHPs have to consult with the nearest relative any way and that there can be conflicts of interest between service users and families. It would add yet another complicated element to the AMHP role if a decision is made to implement this more explicitly.

As most social care review processes already include a sign off by the family or advocate as a true reflection of the conversation, this approach could be considered and it would be great to ensure family and service users views are included. This could be supplemented by training and a case audit of families to obtain their feedback on whether they felt their views were considered and reflected through the process. There is a key role for advocates in this process to work with families and professionals to achieve the right outcome. Advance directives may also be useful – see response in Q11

Qu's 22-24 - Challenging Mental Health Act renewals of detention and decisions on discharge – see attached information 2.27-2.31

Q22 Which of these options (options 1, 2 or 3), if any, do you think would have the most impact?

Three possible options, which are not mutually exclusive, were outlined:

Option 1⁴⁴

Just as for admission, in addition to the patient's responsible clinician, an additional approved clinician or section 12 doctor should also agree that the criteria for renewing detention are met and that this section 12 doctor should be from a different organisation. This could be in place of or in addition to the current requirement to consult a second professional described above.

Option 2

If a person is being treated out of area, one of the professionals (e.g. second professional as now or approved clinician/section 12 doctor as in option 1) involved in agreeing renewals of detentions, alongside the responsible clinician, should be employed by an organisation located within the person's "home" locality. This could be defined either by their LA area of Ordinary Residence or the CCG where resident/GP registered at the point of placement. This input would be funded by the commissioner normally responsible for paying for the inpatient care.

Option 3

That, building on option 1, one of the professionals involved in renewal decisions, alongside the responsible clinician, is both from a different organisation and has strong community knowledge and experience. This might include professionals from Home Treatment Teams, outreach teams, community mental health or learning disability teams, such as community LD nurses or social workers. In line with the principles of choice, the individual or their family or advocate might be able to nominate appropriate potential professionals or organisations they would like to be involved (for example, from providers agreed by local partnership boards).

2.31 We have only covered here decisions around detention renewals. However, the issue of decision making around Community Treatment Orders has also been raised with concerns that this also is less robust in terms of safeguards than original detention decisions. We want to seek further views on this issue.

Option 2 is the preferred option – as this leaves less reliance on an out of area clinician making the decision and presents the most inclusive and collaborative approach; the home commissioner should have some oversight, as potentially they would be funding the 2nd professional. However, family involvement is vital whatever is the preferred option. Would need to clarify how to judge someone has strong community knowledge and experience and to ensure the impartiality of this person. Number 3 would have the most impact.

Q23 Do you have any views on risks or costs presented by any of these options?

Option 1 and 2- Cost is an issue depending on the numbers of renewals- this would need to be clear in order to effectively plan.

Option 3- Capacity is potentially an issue as the cost may be a hidden one- officer time will be required in the case of LD Nurses or Social Workers.

An alternative option could be an exchange in the local area via neighbouring LD Team; local knowledge could be shared as appropriate. This would be agreed on a quid pro quo arrangement, but would need to be proportionate. This solution could be supplemented by the use of life story books or alternative records that the person agrees to share.

If local clinicians are to attend, the cost of travel and time it takes to get to placements needs to be factored in.

Q24 Do you have any views on the decision making processes around Community Treatment Orders and how they could be improved?

No clear process at the moment as to which AMHP should take responsibility and this can cause delays in the system.

For example, there could be potentially three boroughs involved when seeking approval of decision from AMHP's-

- Borough of residence
- Placing Borough (ordinary residence)
- Receiving Borough

There is a need to streamline and clarify the roles and responsibilities and where the responsible AMHP should be located.

There should be a requirement to interview the patient or consult with the nearest relative, where feasible. This links to Question 21.

There is also a need for guidance as to what would constitute grounds to disagree with the consultant's view. There needs to be more support given to improve the knowledge of the responsible clinician.

There is a view that CTO's are not used enough and are rarely considered for PWLD. Should be responsibility to consider CTOs and guardianships as way to speed up discharges. Conditions of the CTO can be very creative and address a real range of issues and risks.

Work needs to be done in hospitals to support people to understand option of CTO and care in the hospital. Need to challenge belief that people automatically do not have capacity to understand a CTO and proper capacity tests take place.

Decision making process – not enough attention paid to MCA to assess capacity.

Qu 25 - Mental Capacity Act – see attached information 2.32-2.42 and Annex C Q25 Guidance could say that only organisations that include self and family advocates in their governance should get contracts with the local authority or the NHS to provide services for people with learning disability or autism. What do you think about this idea?

This would be best practice for tendering and should be standard practice for LAs and NHS. May not be able to keep to this requirement for emergencies. The tensions between family carers and self-advocates would need to be clearly managed. Many people with learning disabilities may already defer decision making to adults (especially parents), access to advocacy through transition is important. There is a need to be clear about what people are asked to contribute to and what is appropriate in specific roles.

Meaningful engagement is required or organisations will be able to get contracts just by having a self-advocate on the board - yet meeting papers are inaccessible and self-advocates are not appropriately supported to contribute in a meaningful way. The infrastructure is vital so it would be more valuable to legislate that organisations have to have the infrastructure in place, ensure that self-advocates have decision making powers and that the governance processes are accessible to people with learning disabilities.

Qu's 26 & 27- Independent Mental Health Advocates (IMHAs) –see attached information 2.43 – 2.47

Q26 What are your views on making IMHAs available to patients who lack capacity (or competence) on an opt-out basis?

Agree that if a patients right to confidentiality is respected an opt out system may work well in improving access to IMHA services. Should increase take up of IMHAs which is a good thing. Early planning to “at risk” groups to establish their wishes should be undertaken and form part of any guidance. Also need to ensure that quality and competence are driven up.

Q27 Have we considered all the safeguards we would need to protect patient confidentiality?

There may be an issue about who makes the decision where somebody lacks capacity and there are tensions with parent/family carers. Needs to be clear how this will be managed.

Qu's 28 & 29 - Nearest relative – see attached information 2.48 – 2.56

Q28 What do you think about the idea that we should explore changing the law so that people choose their own “nearest relative” (retaining a hierarchical list to be used if necessary)?

Good idea in principle if people have capacity to make this decision. Need to ensure that keep right to displace the identified nearest relative if in the persons best interest.

Hierarchical list seen as a good thing. Should be part of advance directive. A very important role and there should be criteria (e.g. must be able to take an interest in that persons life). (Similar to RPR issues for DOLS)

Q29 Do you agree with our view that this should reduce the cost of displacement and disputes?

This depends on establishing the need for change and should be backed up with clearly evidenced data to establish the business case for this. The risks may outweigh the benefits, but difficult to make a case without evidence.

The risks are mainly to the organisation in terms of resources:

- Who is going to collate and maintain the list of nearest relatives
- What if there are disputes among relatives about who should be on the list etc.
- How will these issues be resolved
- Will this impact on officer time when capacity is already an issue

Experience related from one locality suggests that displacements are rare.

Q30 The role of social workers and/or named professionals in supporting people's rights – see attached information 2.57-2.59

Q30 A named social worker could be responsible for working with the person and their family to keep them informed and involved and to make sure less restrictive and community based plans are considered. What do you think about this idea?

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This is a positive suggestion and would make organisations work with social workers. Also enables the social worker to develop a better relationship, better understanding of the person which can only improve the care planning process. Also gives social workers more of an advocacy role / focus which is positive and key to effective social work involvement.

Enables longevity of the relationship which ensure care planning is consistent.

Aligns with principles of WBV concordat. Brings professionals together to achieve the best outcome for individuals.

A named care coordinator would be more beneficial, this may be a social worker.

This is already in place through Assuring Transformation, but the quality of planning (least restrictive setting, person centred) depends on the individual and requires commissioner leadership (oversight and challenge).

Q31 Support and accountability if something goes wrong – see attached information 2.60

Q31 What else, if anything, is needed to support people and families to raise issues if something has gone wrong?

- Effective and timely advocacy arrangements
- Clear, accessible systems (including complaints)
- Appropriate accessible governance arrangements
- LD friendly infrastructure
- Service user involvement audits
- MCA and DoLS audits
- Third party reporting
- Knowledge about safeguarding and whistleblowing process
- Family support group is a good model of practice - can be hard work, but provides families with another way to be heard.
- Possibility of family conferences to discuss issues so all feel they are an equal part of the process.

Section 3. My rights under the Mental Health Act

Qu's 32-33 - Application of the Mental Health Act to learning disabilities and autism – see attached information 3.1-3.8

Q32 Which of options 1), 2) or 3), if any, seems most appropriate?

Option 1: expressly exclude both learning disabilities and autism from the MHA

Option 2: amend the definition of “mental disorder”, by tightening the “learning disability qualification” and adding a new “autism qualification”

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Option 3: exclude learning disabilities and autism from the civil sections of the Mental Health Act (part 2) but not the criminal justice sections (part 3)⁵⁹

Some of these options feel unnecessary after a massive CoP consultation and in view of potential changes to DoLs and MCA once the Law Commission has completed its work in these areas.

All options have limitations but Option 2 is probably the best way forward, but with some concerns about court diversion for offenders.

With option 1, concerns that PWLD who need support may not be able to access it. Don't want people sectioned just because they have a LD, but don't want them to lose access to it. Note concerns of LD advocacy and disability groups that MHA as it stands may not meet article 12 of HRA.

PWLD can be sectioned under the MHA if their behaviour is deemed to be "irresponsible" - needs better definition.

Need to define how PWLD would continue to be able to access to support in prison currently available so they have some sort of protection.

If statutory mechanism is no longer there, needs to be a mechanism to enable access to treatment and admission to hospital - need a more appropriate definition.

Q33 What is your view on the potential benefits or unintended consequences of the options set out?

Some of these options feel unnecessary after a massive CoP consultation and in view of potential changes to DoLs and MCA once the Law Commission has completed its work in these areas.

Needs to be noted that a significant proportion of adults with ASD and some people with learning disabilities are not diagnosed. This could result in people being sectioned when in fact the new autism qualification should be applied.

Q34 - A single gateway to MHA assessment and treatment with a single clearer set of safeguards – see attached information 3.9-3.13

Q34 We want to explore changing the law so that there is one set of criteria for detention for assessment and treatment under the Mental Health Act (amending sections 2 and 3). What do you think of this idea?

Unclear as to the intention of the Green Paper on this point. Is the proposal that Sections 2 & 3 be replaced (or merged) by one entry process or, will the single gateway determine whether you are dealt with under Section 2 or under Section 3? Clarity is needed on this.

Q35 - NHS commissioners and the Mental Health Act – see attached information 3.14-3.16

Q35 We propose to clarify in law that the Mental Health Act Code of Practice should apply to clinical commissioning groups and NHS England commissioning. What do you think of this idea?

This seems appropriate

Qu's 36-40 Interactions with police and the criminal justice system – see attached information 3.17-3.23

Q36 What is your view on the proposal that children and young people aged under 18 detained under sections 135 or 136 should never be taken to police cells?

Q37 What is your view on the proposal that the use of police cells for people aged over 18 should be more limited in terms of frequency and length of time they can be detained?

Agree. Should be the last option (again, need alternative option) and time limited.

Q38 What is your view on any other recommendations in the Review?

Q39 What is your view on the review proposal to create powers for professionals other than the police to be able to take a person from a public place to a place of safety?

As s135/s136 are already under review following the recommendations of CQC, these interactions would be better addressed through that process.

With all the questions above, there would need to be alternative options available.

Q40 Are there any practical considerations we should take into account during further developmental work and implementation of the Review proposals?

As response to Q39

Qu's 41-42 Restricted patients: discharge with conditions – see attached information 3.24-3.31

Q41 Do you think it would be desirable in principle to amend the MHA to enable restricted patients to be discharged by the Secretary of State for

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Justice or a Tribunal subject to conditions amounting to a deprivation of their liberty?

Very good proposal and offers a lesser restrictive option.

Q42 Does the MHA need to provide for another form of detention for patients who do not need to be in hospital but who must be in effect deprived of their liberty in order to be discharged from hospital into a community based setting?

Yes in principle as allows for discharge that is not currently available and will enable consistency. Needs to link to wider reviews eg. Bradley report. Unclear what other options for detention would be.

Section 4. My right to control my own support and services with a personal budget. My right for my NHS and Local Authority to work together for my benefit

Qu's 43 - 45 Integrated planning, personal budgets – see attached information 4.1-4.18

4.17 To build on the actions set out above, we are proposing introducing a legal right to have a personal health budget for some people with learning disabilities or autism. We are considering two options, which are not necessarily mutually exclusive, either:

Option 1:

- *Aimed at the, up to 3,300 people with learning disability or autism and either mental health problems or behaviour that challenges who are currently in inpatient institutions. This would be targeted to help those where there is no longer a justifiable clinical or legal ⁷⁴ reason for them to be there, move back into the community. The aim of this is not to change the way their institutional care is paid for, except in exceptional circumstances, but rather help them to be discharged and then live as independently as possible; or*

Option 2:

- *Aimed at those people with learning disabilities who have mental health needs or challenging behaviour and are subject to the Care Programme Approach ⁷⁵ whether in the community or institutional care.*

Q43 Which of the options (option 1 or option 2) do you think would be most effective?

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Option 1 is the priority for personal health budgets and is pragmatically achievable, as there is slow progress nationally to enable people with learning disabilities with more complex challenging needs to leave institutional settings. However it would be very helpful if people with learning disabilities subject to the CPA could get access to a personal health budget. For example, it would be easier to commission specialist therapy for people at risk of sexual offending. However, there would still be a need for better community provision to enable effective use of personal health budgets. There would also need to be clarity/guidance on who would or could manage the PHB.

Q44 What else might need to happen in order for such Personal Health Budgets to enable people to choose new providers and/or new kinds of service or interventions?

- A provider market for services for people with more complex and challenging needs development , and more choice available locally
- Appropriate care and support from experienced and trained practitioners which reflects a whole systems approach
- National Directives to set up whole systems approach
- Permanent housing that is sufficiently spacious/ adaptable to meet peoples specific needs – both physical as well as behavioural
- A local climate of working well with partners to ensure a whole systems approach
- Independent advocacy
- Online accessible info on services that are out there
- National quality standards for providers that are clearly communicated to families
- Workforce development so that hospital staff can inform of and promote PHBs

Q45 How can we ensure that the new arrangements under the Children and Families Act can also be used to prevent unnecessary admissions in adulthood?

- Robust transitional arrangements across the whole health and social care economy to ensure families experience no gaps in provision
- Early assessments and preparation with young people to ensure a smooth transition
- Good information and advice from an early stage
- Good liaison between CCGs and Las
- 'All age' local commissioning plans

- EHC plans are comprehensive and include housing and any mental health needs
- Using EHC as a crisis prevention tool
- Good relationships between LA and NHS

Qu's 46-47 – Pooled budgets – see attached information 4.20-4.26

Q46 We could seek to set up and mandate specific pooled funding, with joint planning, to help people with learning disability and/or autism get discharged from hospital or help prevent them being admitted. This could include specialised commissioning funding. What do you think of this idea?

We would welcome this idea provided that any central commissioning is delegated to enable local decisions/ actions with minimum bureaucratic delays. This should enable the development of new services and have money available to respond to needs; should support quicker responses. Funding should follow the individual.

Q47 Are there further ways we could strengthen local accountability, particularly to disabled people and their families?

- Ensure Health Watch is well publicised and there are strong links with any learning disability Parliament, Carer's Groups, local Partnership Boards and Health and Well Being Boards.
- Link into other initiatives such as Driving up Quality, Social Care commitment, Health Charter for providers.
- Have more disabled people and their families in governance structures. Money available to train and develop families so they can participate.
- Don't just rely on meeting attendance - online chats/ feedback; being involved in the way people want to

Q48 - Information sharing – see attached information 4.27-4.35

Q48 We want to explore whether providers of specialist hospital services and residential care services should be allowed or have a duty to share confidential patient information with case managers and other relevant commissioners directly involved in arranging a person's care in certain circumstances. What do you think of this idea?

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Some contracts with providers already specify that the provider must share records with LAs. Some providers have information sharing arrangements with clients which makes it clear that they are required to share information with the LA, to ensure that the provider is providing a good quality service as specified in the person's support plan. It would be helpful if there was a legal duty to share information with the care manager or commissioner and a national directive to understand Data Protection Act challenges.

Where this happens it is generally very positive for the individual.

Section 5 - Physical as well as mental health

Q49 I want to know who is responsible for supporting my physical as well as my mental health – see attached information 5.1-5.9

Q49 What are your views on how we could be clearer around responsibilities of:

- ***clinical commissioning groups***
- ***providers***
- ***medical directors; and***
- ***responsible clinicians***

for the physical healthcare of people in mental health inpatient settings?

All proposals outlined in 5.9 would be useful. LD hospital passport and Health Action Plan are key to this and getting personalised support.

The recommendations from the confidential inquiry should be taken into account when framing this guidance.

There are examples of good practice in local areas. For example, learning disability hospital passport being used when a client goes in hospital and reflecting all the information in the last Health Action Plan.

One area has KPI's with the mental health provider to ensure Primary Care is communicated with regarding any admission, and that physical checks are attempted on all admitted patients. For example, that 98% of all inpatient service users have a physical health assessment at least every six months

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Reach Standards could be included in provider requirements and the PLD Quality Assessment Framework, which includes health management, used to assess if a service is safe and appropriate, including in-patient facilities.

Q50 This is an exploratory consultation which sets out a range of potential options on which we want to hear views. The proposals in this paper do not all need to be taken as a single package of measures.

Thinking about all the things described in the document:

- ***which would have the greatest impact and benefit on people's lives?
(so we know what should be highest priority)***
- ***which carry the greatest potential costs or risks?***

Greatest impact:

- Improving community provision across London area
- Would be very beneficial to improve collaborative working across regions
- Professionals involved in admission process have good specialist knowledge relevant to learning disabilities, autism and mental health
- Change of definition of LD; change of section criteria for admission
- Establish pooled budgets for service developments
- Have regard to factors that include a person's community inclusion
- Better engagement of family carers/parents
- Sharing info that is transparent, clear and understandable

Greatest potential risks/costs:

- Lack of seamless approach in joining learning disability and mental health services particularly 24 hours
- Not enough positive behaviour support knowledge in community services
- Essential there is clarification and confirmation that proposals with new costs are fully funded