



Association for Real Change (ARC) response to the consultation to the Green Paper – No voice unheard, no right ignored a consultation for people with learning disabilities, autism and mental health conditions.

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Introduction

Association for Real Change (ARC) is a leading umbrella body representing 150 service providers in the learning disability sector in England – our purpose is to improve the quality of life for people who have a learning disability by supporting anyone who is involved in the planning or delivery of support and services.

We provide a range of services such as high quality information, networking opportunities, learning disability training, qualifications, publications, and Disclosure checks.

We are pleased to comment on this important Green Paper. Many of our members have experience where the system has got it badly wrong for individuals. We are concerned that the Green Paper does not go far enough to draw in providers of support, or recognise the essential knowledge and expertise that there is in the sector.

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 the NHS commissioners should have the same duties, for example, for people with a learning disability or autism who are at high risk of long term stays in hospital in relation to their lifelong needs. What do you think of this idea?

Well-being should already be a fundamental principle for NHS commissioners, we are absolutely of the opinion that NHS commissioners should have the same duties.

Q2 In making decisions on living arrangements (whether suitable accommodation or inpatient stays) LAs 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?

We believe that factors that support inclusion in the community are already embedded in existing human rights law, and are enshrined in clause 1 of the Care Act 2014. The challenging question is why this consideration is not already the case? It is extremely frustrating for our members that they are not drawn into processes early enough to create good and imaginative support for people that meets their needs in settings that they choose.

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

We don't feel that it is possible to state what would be an appropriate length of inpatient stay. We do however believe that as soon as a patient is admitted a plan to move to discharge should be robustly put in place. Discharge plans should be monitored through CQC inspections and by commissioners. It is essential that existing protections under the Mental Health Act are adhered to. Existing providers supporting individuals should be involved in this process, if new providers of support in the community are required these should be brought into the process at an early stage.

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

It is essential that there is joined up working between LAs and the NHS. There needs to be a shared approach to prevention and there needs to be suitable and adequate provision in both settings. Our members often feel caught in disputes as to who should be paying for care and whose responsibility it is. This does not mean that the needs of individuals are being put first (or that the first principle is their well-being).

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

Yes, we agree that there should be a joint approach, but feel that this needs to be worded more strongly than a suggestion to 'think about' ensuring community based support.

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

There must be a person centred approach to each individual who demonstrates this level of need. LA's and NHS commissioners should be aware of potential need within their communities, for example by continuing to track individuals who have had a statement of educational need. A joint commissioning approach should be taken that ensures effective use of both local authority and NHS resources in community based settings. Whilst we would want hospital settings to be only used as a last resort where it is necessary to provide a hospital based approach this needs to be of high quality, centred on the individual and outward facing, focussing on enabling

people to be supported in the community as soon as possible. Partnership working is essential.

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

We are not able to offer an evidenced view on the likely costs of such a duty. Our experience, however, would suggest that where LAs and the NHS work well together putting the needs and rights of the individual first there should be potential to minimise risk and make long terms savings.

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 Professional and doctors have to consider and record whether assessment and treatment could be provided without detention in hospital.

We are fully supportive of this suggestion. Our current understanding of the Human Rights Act, however, is that a lack of provision in the community is not a valid reason for keeping an individual under section.

Q9 What is your view on the likely cost or impact of this idea.

As with our answer to Q7 we are unable to give an evidenced view. We believe that there would be saving long term. This area is a strong contender for shared budgets, we are concerned that potential disputes about funding and responsibility between LAs and the NHS could compromise the intention of this proposal.

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?

We are fully supportive of this proposal, although we believe that this should already be the case. We feel that the right to an advocate should form part of this provision. We are concerned that individuals who are under section and who have a learning disability may not have the access to formal legal support to which they are entitled, this entitlement should be reinforced in guidance.

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

Yes we agree with this proposal.

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

We strongly agree with these proposals.

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

There has to be joint working between the NHS and LA's in order for the mechanism to be able to function. Community provision has to be suitably resourced with a robust process of ensuring that there is capacity. This will also require close relationships to be developed with providers and for commissioning to be imaginative and creative.

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

Without statutory force behind the mechanism, especially with current budget pressures, we feel it would be unlikely that it would be implemented.

Q15 What do you think of the idea of strengthening (for example in statutory guidance) peoples rights to request a transfer to a less restrictive setting or a setting closer to home or to ask for a discharge?

We are supportive of this proposal.

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

Yes, we feel that this is essential. We would want to emphasise here the knowledge and experience of providers of support. It feels as if this is sometimes written out of the paper.

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

There needs to be a clear, transparent process, that is easy for individuals and their carers to understand.

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 the new statutory guidance (complementary to the Mental Health Act Code of Practice). What do you think of this idea?

We agree with this proposal and believe that new statutory guidance would ensure that this was implemented.

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, we believe this is essential. This is an area where existing are staff must be involved in the process if appropriate.

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

We are concerned that existing policies and guidance are focussed on older people and do not serve younger people with learning disabilities and mental health problems well.

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 and 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 the process might work).

We are supportive of this idea but would want to see a clear link with this to the proposals in 2.8 -2.11. It is vital that people have entitlement to an independent advocate in this situation, which would be in line with the Care Act 2014 and the Mental Health Act.

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

We feel that Option 3 is preferable. We are less concerned about potential conflict of interest than about ensuring there is expertise around what is achievable in community settings present in the decision making process.

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

We feel that Option 3 not only presents the potential for delivering the best outcome for individuals but is also likely to be cost effective, as it will ensure there is the expertise required brought into this stage of the process.

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

We feel that Community Treatment Orders should be subject to the same rigour and review as detention renewals.

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?

Whilst we agree with the intention behind this recommendation we are not convinced that a requirement, for example, to have a person with a learning disability on the board of an organisation would achieve the desired commitment to advocacy throughout an organisation. We are concerned that

this imperative could lead to tokenism and not have the desired change in practice. We would want to see this intention more fully developed with consideration given how the voices of individuals who would find participating in governance structures extremely challenging can be heard.

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

We are supportive of this proposal. We are concerned that in the current setting people with learning disabilities who have the right to an IMHA are not offered this support. We feel that the right to an advocate is cross referenced to the right to an independent advocate in the Care Act 2014.

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

We feel that safeguards have been considered appropriately. There is a difficulty that partners in the care and support of an individual may be excluded from the process but this may compromise working towards a speedy discharge to the community, especially in the case of people who lack capacity.

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)?

We would support this idea, we believe that this would only work if a hierarchical list was kept to be used if necessary.

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

We feel this needs to be put in place because it is the right thing to do. We don't think, however, that this will prevent displacement and disputes and may create some very difficult situations in establishing who is the nearest relative and potential conflict within families.

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?

Yes, we feel that this would be good practice.

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

We do not feel it is easy for people and families to raise complaints, especially in large organisations or if there are several providers involved in an individual's care and support. People will often be reluctant to complain

because they are concerned that this will affect their, or their relatives, care and treatment. We would particularly want to see CQC inspectors taking time to communicate with people receiving support and their families to identify issues. We feel there is scope for regular 'drop in' inspection services to be undertaken similar to the inspections taken by independent custody visitors.

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

We agree with the principle of separating learning disability and autism from the Mental Health Act. We have struggled to support any of the options as laid out in 3.8, however, as we are concerned at the potential for there being unintended negative consequences. We are most drawn to Option 1 and would hope that the deprivation of liberty safeguards may be sufficient to ensure that people receive appropriate support.

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

We share the concerns raised in 3.8. As stated earlier in our response there needs to be careful joint working between LAs and the NHS so that support is built around people appropriately.

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.

Yes, we would support this proposal.

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?

We are fully supportive of this proposal.

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?

We are fully supportive of this proposal.

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?

We do not feel that a police cell is ever appropriate for someone with mental health issues. Appropriate provision urgently needs to be developed to minimise risks to people. In the meantime we would like to see limitations on the length of time and frequency people may be held in police cells.

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

We do not have any further comments to add to 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.

We are uncertain about this. There need to be tight safeguards in place as to who may be able to undertake such a task, for example people would need to be trained in the safe use of restraint.

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

We have no further comments other than made in our responses above. We feel it is essential that providers of support for people with learning disabilities are consulted as the developmental work is taken further. As an umbrella body we would be willing to participate in such a process and share our experience.

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

We believe it would be desirable in principle to amend the MHA to enable restricted patients to be discharged by the Secretary of State for Justice or a Tribunal subject to conditions amounting to a deprivation of liberty.

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 we feel that this is essential to ensure the principles outlined earlier in this consultation can be implemented.

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

We would want to see both options employed, whichever it most likely to achieve positive outcomes for the individual.

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

There needs to be choice in the market. People need accessible information. As well as information individuals and their families may also need an

independent advice service. It is essential that professionals working with individuals are aware of the various options that may be available.

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?

There should not be a drastic demarcation between children's and adult's support. There must be communication across services when an individual is in transition. It is important that providers of care and support are brought into the process of transition at an early stage. That a range of options are available to individuals and that LA's collect data to enable forward planning to take place.

Q46 We could seek to set up and mandate specific pooled funding, with joint planning, to help people with a 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 are in agreement with this idea.

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

There must be clear information and resourced support and advocacy groups.

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?

We believe that this will be essential to guarantee positive outcomes for individuals.

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 settings?

We believe that this needs to be specified in statutory guidance.

Q50 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 the highest priority)*
- *Which carry the greatest potential costs or risks?*

We believe that a joint commissioning approach is vital. This must include shared budgets so that individuals are not caught in disputes about who pays for what. Commissioning must be outcomes focussed and person centred with a first assumption that individuals will be supported within their communities. This requires strategic needs analysis to be carried out and investment in developing a range of support to meet future needs. It is essential that people with learning disabilities and autism have their rights supported at key moments, including the provision of high quality advocacy services.

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