



RIGHTFUL LIVES 8 POINT PLAN CONSULTATION

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Summary

In May 2019 the Rightfullives team were asked by a journalist what sort of changes we would like to make to the inpatient hospital system and the way in which people with learning disabilities and autistic people are supported. Because the journalist was in a hurry, we quickly came up with our Eight Point Plan, but we knew that our ideas on their own aren't enough so during May and June we consulted on our plan. Survey Monkey to host the survey and the results have been reviewed and analysed by Mark Brown, Elaine James Chris Hatton.

As a result of that consultation and in response to the views that people have expressed, the 8 Point Plan has changed. The changes have had to reconcile the widespread support that the 140 respondents have given to each of the eight points of the plan, with the need to incorporate the themes raised by the 347 comments that people have made.

The Revised Eight Point Plan

1. A review and plan for everyone in an in-patient hospital to get community support within 12 months or sooner;
 - a. Including a strengthening and greater focus on the use of CTRs and CETRs;
2. Steps should be taken by all responsible bodies to ensure that individual's rights under existing legislation are being met and that public authorities and publicly funded bodies are meeting their statutory responsibilities;
3. The establishment of an independent body led by people with learning disabilities, autistic people, families, lawyers and representatives of key stakeholder organisations, that has the remit to monitor and hold responsible bodies to account, in accordance with the requirements of existing legislation.
4. Increased funding and investment in community services, preventative support and in the transition from inpatient hospitals.
 - a. Including the funding of specialist teams (Hit Squads) with people who have expertise to help stop people being detained under the Mental Health Act.
5. Families' and friends' right to visit, when a family member or friend has been detained under the Mental Health Act 1983, being properly enforced and work undertaken to prevent the misuse of current legislation by providers and commissioners in inappropriately silencing and gagging families, friends and advocates;
 - a. Including the right to speak publicly about an individual's detention in accordance with current legislation where this is with their consent or in their best interests;
6. Information and transparency about local area and national plans to support and meet the needs of people with learning disabilities and autistic people, the numbers of people in inpatient hospitals, where they are, how much money is being spent and by which commissioners.
7. STOMP (Stop over medicating people) to be part of all NHS and private health care practice.
8. In the longer-term, support legislative change to strengthen people's right to independent living and a life free from the threat of detention, with community alternatives to hospital care:
 - a. Drawing on the principles outlined in the Draft Disabled People (Community Inclusion) Bill 2015, also known as "the #LBBill" so that laws and home admission considered first;
 - b. The United Nation's Convention on the Rights of People with Disabilities;
 - c. Giving CTRs and CETRs statutory powers;
 - d. Including strengthened rights to advocacy and independent support for people without families or whose families are not involved in their lives;
 - e. Rights to peer advocacy and visits from friends and people who know them well;
 - f. And strengthened rights for families whose family members have been detained.

What we did

During May and June 2019, Rightful Lives ran a consultation into an 8 Point Plan for getting learning disabled and autistic people out of Assessment and Treatment Units and Long Stay Mental Health Hospital Beds. The consultation was hosted on a web site and publicised through social media on the Twitter and Facebook platforms. Participation was voluntary and open access. A unique ID was recorded for each unique IP Address accessing the web link to the survey. One hundred and thirty-nine unique responders were recorded.

The consultation asked for respondents to select from responses on a Likert scale how important to meeting the ambition of getting people out of hospital they thought each of the proposals in the 8 Point Plan were. Respondents were then provided with an opportunity to give further detail in a free text box.

The original 8 Point Plan proposals which were rated were:

1. A review and plan for everyone in an Assessment and Treatment Unit (ATU) to get community support within 12 months.
2. An independent body led by people with learning disabilities, autistic people, families and lawyers that has power to monitor and direct commissioners and can remove power from commissioners that are failing.
3. Ring fencing money just for community services and the transition from Assessment and Treatment Units.
4. Families being given rights to visit when their family member has been detained under Section of the Mental Health Act 1983 and being allowed to speak out publicly about it.
5. Information about the numbers of people in ATUs, where they are, how much money is being spent and by which commissioners, is made publicly available.
6. Funding of regional 'hit squads' with people who have expertise to help stop people being detained under the Mental Health Act.
7. Support for the proposals of the Disabled People (Community Inclusion) Bill 2015, also known as "the #LBBill" so that laws and systems change to safeguard people's right to have community alternatives to a hospital or care home admission considered first.
8. STOMP (Stop over medicating people) to be part of all NHS and private health care practice.

In addition to this we asked people if they could think of any points that they felt should be included. The consultation period ended on the 16th of June we then began the process of processing and analysing the results.

Whilst we have been incredibly impressed by the response to the consultation, we are aware that some people with learning disabilities will have found the consultation method difficult to access and would prefer to have been involved in face to face consultations and other more accessible approaches. This is undoubtedly an important issue. As we seek to take the plan forward, it is our intention that it will continue to evolve. As it does so we will hopefully be able to work with other organisations to ensure that the views of people with learning disabilities, who were unable to take part in this stage of its development, are at the centre of the plan as it does.

Results

The results from each question have been presented in a clustered bar chart with the numbers of respondents in each category displayed in each column. In the text we also usually describe the proportion of people who indicated that they felt that a proposal was essential to the plan and or very important.

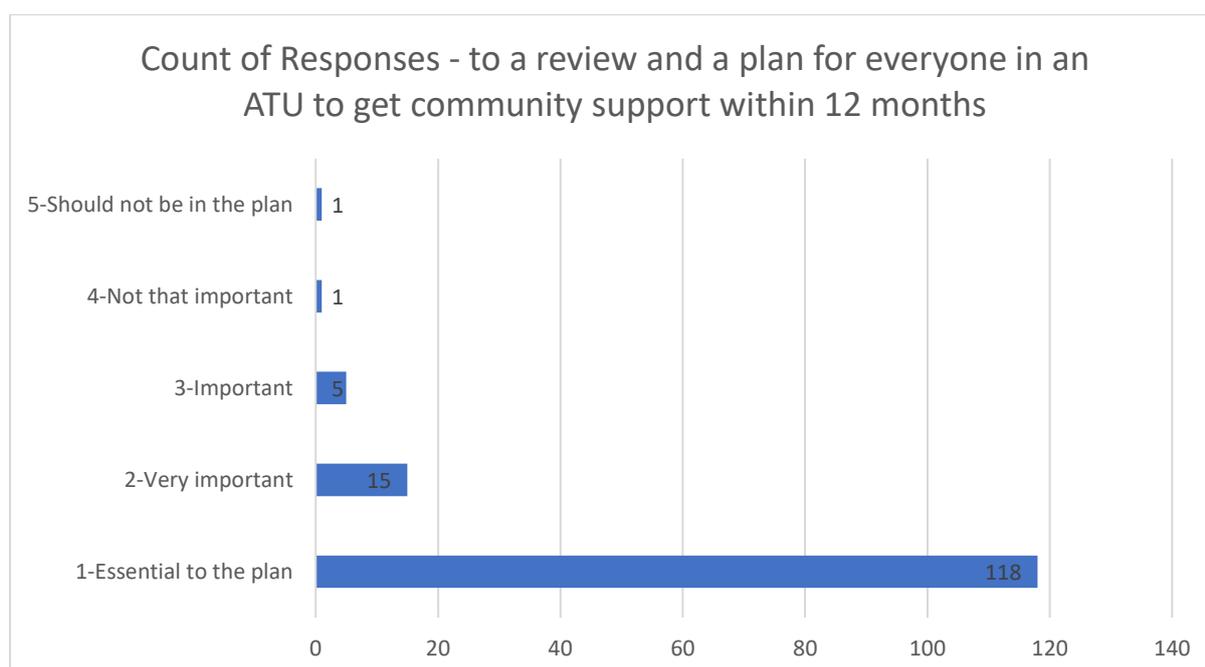
In total there were 347 comments to the 8 different proposals, each of which was initially coded into one of three categories:

- Supportive - Comment is directly supportive of the proposal
- Expansive - Comment expands on the original proposal
- Challenges - Comment challenges the original proposal

The comments were then analysed to identify the themes within the narrative of the text and then these themes were then grouped using Excel into over-arching themes or meta-themes which relate to different policy areas and domains. The principal themes identified in response to each proposal are listed here along with examples of the comments that people have made.

More detailed data outlining the proportions of all responses and including all of the comments, is available in the data pack.

A review and plan for everyone in an ATU to get community support within 12 months



118 people or 84% of respondents indicated that it is essential that everyone in an ATU should have a review and a plan that would enable them to return to their communities within 12 months. When combined with those who thought it is “Very Important” the total rises to 95%.

In total 88 people did not feel the need to comment on this proposal. Of the 49 that did, 29 of those comments were categorised as “expansive” in that they appeared to support the proposal but added additional suggestions and depth. While 16 challenged the proposal, mainly commenting that the length of time is too long. As explained earlier the nature of these suggestions have been coded according to two different kinds of theme: narrative-themes and overarching or meta-themes.

The overarching themes identified as additional factors and coded as expansive that need to be considered in response to this proposal were themes of

- Accountability
- Community Infrastructure
- Legislative Framework
- Speed of Action
- Quality
 - Workforce
 - Unsuitability of ATUs
- Collaboration
 - With Families
 - With providers
- Planning
- Funding and Resources
- Systemic Failure
- Isolation and Abuse
- Institutionalisation

Many of the comments incorporated a number of meta-themes into the comment’s narrative. For example, the one below which included narrative themes of lack of accountability, CTRs needing statutory weight, urgency from govt, the state of community services, and the importance of getting it right:

It is important that everyone has a review, but the main issue seems to be lack of accountability across agencies for taking action once a plan has been developed. The CTR needs to have statutory weight, in terms of ensuring everyone has regular CTRs and in terms of putting some teeth behind whatever is agreed within the CTR. There should also be a statutory code for carrying out the CTR (similar to DoLS and the MHA and MCA) so that there is an expectation of good practice in carrying them out. At the risk of being cynical, the current state of community services might make it difficult for some people to move out within 12 months. A sense of urgency from government is needed in terms of how it formulates policy, but there also has to be wiggle room to ensure that time based targets don't lead the agenda, when the focus should be getting people the right support - I think this has been a major failing of Transforming Care.

The themes of lack of accountability and people and organisations taking responsibility for ensuring that plans are delivered was a theme that was expressed in of number of people’s comments in relation to this proposal.

Need to be clear who is responsible for making the plan happen and there needs to be a shared responsibility for making it happen

Another factor identified as playing a role in delaying people's return to their communities, is the role that the legislative framework plays. A number of the people who commented, stated that Care and Treatment Reviews should be given statutory weight, whilst others suggested that the Mental Health Act needs to be reviewed or amended

...as well as this, the MHA needs to be reviewed as a top priority. If autistic people/people with LD can't be sectioned on the basis of that disability, then the number of people receiving inappropriate care will hugely decrease.

Although one respondent argued that the proposal:

is essentially embedded in the principles of the MHA for people on a section, as is their involvement in any care and treatment plans developed. Statutory advocacy should also be provided for support to the individual in these plans, especially those without family's.

A significant theme to emerge from people's comments in relation to the proposal for "A review and plan for everyone in an ATU to get community support within 12 months" was the role that a lack of community infrastructure and support plays in delaying people's return to their communities:

...A plan is great but won't work if [you] can not identify suitable support team and suitable property in the community to meet the persons needs. We need to be careful we don't create a one size fits all solution and maintain person centred discharge. Too often people are discharged back into the community into the wrong place with the wrong type of support and it doesn't work so we end up with a revolving door. Some actual research into what the blockages are in the community and why people are admitted in the first place would be helpful then we could develop evidence-based solutions instead of politician led solutions.

And

A plan to include short term goals including commissioning local services -to enable plan realisation

Related to this are the difficulties that uncertainties around funding can cause for local providers and organisations.

We have to bear in mind that community providers need a level of assurance that commissioners will fund. Many instances where they build / convert then the person is sent somewhere else! It's ok having a plan but we have to have staff with skills to manage behaviours that challenge to ensure they don't return to ATU's or worse end up in secure care eg low

With regard to the 12 month time-schedule a number of people, whose response to the proposal was categorised as "challenges", argued that the 12 month time period is too long, and one that being in an inpatient hospital for 12 months was long enough to institutionalise somebody:

I would say within 3 months. A lot can happen within 12 months i.e. disabled inpatient's health can deteriorate or institutionalisation will set in and worsen. I speak from doing peer advocacy work. One of the issues is that the longer the patients are in hospital the harder it is for a good and successful discharge. 12 months in an institution is a life time for many inpatients! Also community support is one aspect, housing and structured days of purposeful activities as directed by the patients.

And

Is a shorter timescale possible eg six months. A year seems too long

Or as one respondent put it:

Just to get out of hell hole asap.

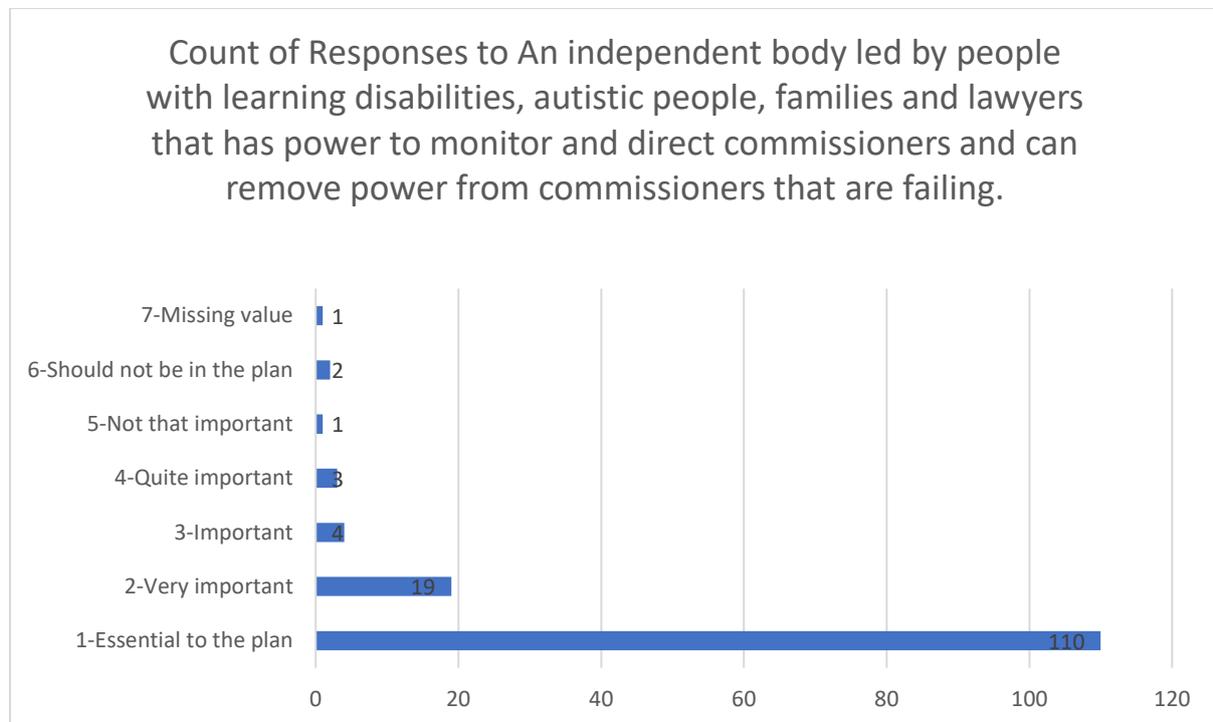
Another challenge to the proposal was that the time-schedule should be person centred and set according to the individual's needs.

Needs to be on a case by case basis. Not everyone will be ready for discharge within 12 months and moving them out too early can do more harm than good

And that the need for a person centred focus, should extend beyond the time schedule

This should already be happening in an assessment and treatment unit - reason for continued admission should be clear alongside what assessment and treatment is taking place. Should be being reviewed much more frequently than annually. A plan is great but won't work if you can not identify suitable support team and suitable property in the community to meet the persons needs. We need to be careful we don't create a one size fits all solution and maintain person centred discharge. Too often people are discharged back into the community into the wrong place with the wrong type of support and it doesn't work so we end up with a revolving door. Some actual research into what the blockages are in the community and why people are admitted in the first place would be helpful then we could develop evidence-based solutions instead of politician led solutions.

An independent body led by people with learning disabilities, autistic people, families and lawyers that has power to monitor and direct commissioners and can remove power from commissioners that are failing.



110 people or 79% of respondents indicated that it is essential to the plan, that *an independent body led by people with learning disabilities, autistic people, families and lawyers that has the power to monitor and direct commissioners and can remove power from commissioners that are failing*. And combining the proportion of those who thought that the proposal is very important with those who thought that it is essential indicates that 93% of respondents strongly support this proposal.

In total 97 people did not comment on this proposal. Of the 42 people who did comment on the proposal, 31 of the comments were “expansive”, 5 were “supportive” and 7 made comments that “challenge” the proposal.

The overarching themes that we can identify in the 30 expansive comments made in response to this proposal were:

- Accountability, Monitoring and Quality
- Legislative Framework,
- Collaborative working
- Disabled people led organisations
- Poor integrated working
- Medical Model,
- Inclusion and Rights
- Systemic issues
- CQC
- Regional integrated working
- Training, professional development

- Collaboration and family support
- Information

Of the responses that drew on the overarching theme of collaboration a number cited the need to incorporate the views and knowledge of people with learning disabilities, autistic people and their families as an important factor:

Involvement of individuals with a learning disability/autism and their families is the most important in these points, as I think it will be what drives change.

And

How things are presently are not working! It doesn't mean people with lived experience of learning disabilities / autism / families make all decisions but lawyers / professionals MUST start listening to and taking on board views from those with lived experience!

In addition to a need to ensure that the knowledge and perspective of people with learning disabilities and autistic people is taken account of, respondents also argued that the body would play an important role in holding the system to account and in improving quality and outcomes.

This is very important, particularly in relation to commissioners. The CTR was meant to bring in lived experience to each person's care and treatment planning, but this is done in a patchy way. Where people with lived experience do have an input, it appears that the outcomes for the individual are much better. An independent body should have clout when it comes to commissioners, both in terms removing those that are under-performing and in terms of sharing good and innovative practice with commissioners who aren't thinking outside of the box. A significant barrier at the moment remains ignorance among commissioners of what support options are out there for people who may be labelled as 'too challenging' to ever leave hospital. Another function of this body could be quality reviewing, which has been a successful model used in learning disability services, to audit the service that people receive. The independent body could shadow the CQC's inspections and produce parallel reports, which would likely increase scrutiny on the regulator's assessment of how services are performing. Although they should not dominate the body, there is a role for good providers to play in an independent body. There are a number of good service providers who have good insight and are committed to best practice, who would be able to bring knowledge and expertise to the table when it comes to holding commissioners to account. A pre-condition of involvement might be making sure that any provider involved would have to support an expert by experience to participate in the independent body.

The suggested involvement of providers is also made by another respondent who suggested that the body:

Should also include relevant not for profit/charitable bodies such as Human Rights bodies, self, peer and statutory advocacy groups, carers support organisations etc.

The need for broader changes to the system and the legislative framework was made by two separate respondents the first would appear to be a commissioner who makes the following observation:

From personal experience if you're a commissioner fighting to do the right thing it can be a really lonely and stressful fight to have. The system isn't set up to make it easy to do the right thing sometimes. That isn't an excuse for the awful things happening but it would be good if something like this could also help those commissioners who are trying their best to have more chance of making the right thing happen.

The other respondent, advocating for broad changes to the system and legislative framework

In order for this to be effective, NHS and Local Authority commissioning needs to be radically restructured, alongside a National Independent Living Scheme, run locally by non-profit co-operatives. This also requires repealing the Health and Social Care Act 2010, and as a minimum The Care Act 2014 to include a right to independent living, in consultation with Deaf and Disabled people's Organisations, Self-advocacy Organisations, Autistic Pride and User-led Psychiatric Survivors groups, in-line with UNCRPD. [Also] The CQC should be replaced by a genuinely accountable and representative organisation.

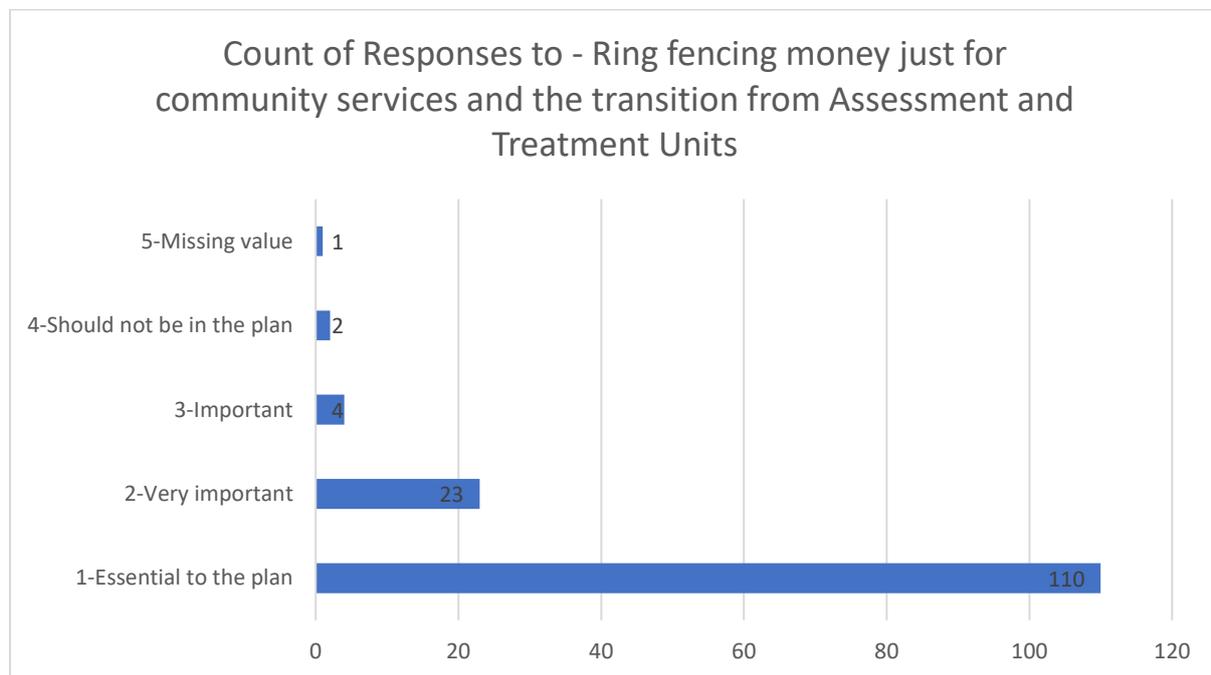
The scale of the changes that would need to be made to the system and concerns about feasibility is also raised in a number of the challenges to the proposal:

Would have been good to have a NOT SURE option here. Would be good to understand - What will this independent body be scrutinising? How will this independent body remove power from commissioners and what will that mean in practice? Also how is this different from / will it align with CTR panels? Will they also be able to scrutinise the data - so that commissioners don't downgrade / mislabel people.

And one respondent went as far to state their opinion that:

Not possible within current law. Might be a way in which advisory body could be established but would not have the powers you are proposing

Ring fencing money just for community services and the transition from Assessment and Treatment Units



110 people or 79% of respondents agreed that the proposal to *ring fence money just for community services and the transition from assessment and treatment units* is essential to the Eight Point Plan, with a further 23 people or 17% stating that it would be a very important part of the plan. So, in total 96% of respondents indicated that this is a very important or essential part of the plan.

In total 44 people commented on this proposal. Seven of those comments were directly supportive, 36 were expansive comments and two challenged or disagreed with the proposal. The 36 people who made expansive comments raised the following overarching themes the majority of which were unsurprisingly related to funding:

- Funding
 - Progress
 - Personal Budgets/Person Centred
 - Human Rights
 - Transitions
 - For Profit Providers, Community infrastructure
 - Delays discharge
 - Pay awards
 - Workforce
 - Scarcity
 - Flexibility
 - Preventative
 - Re-structure funding
 - Funding- Person and community centred
 - Funding - NHS/For Profit

- Funding-legislative framework
- Community infrastructure
- Inclusion
 - Access to mainstream services
- Commissioning
- Joint commissioning/ Integrated working
- Re-structure funding
- Financial penalties

So, for example lack of progress and the issues of delays in people being discharged and the funding needed for transitions, was mentioned directly or indirectly in a number of comments including the following:

This is the most important point. I think a lot of the issues comes down to funding and transitions can be halted because money isn't there. The effect of this is prolonged stays in hospital.

And

This would mean haggling between different budget holders would no longer delay discharges.

And

I have sat in on too many discussions about how the funding in social care doesn't allow for high cost ATU transitions. A ring fenced budget to do this is the clearest way of stopping this silliness.

Whilst most people supported the proposal to ring fence funding, a number commented that the funding needed to be used flexibly:

Immediate flow of money on discharge and penalties for hold ups and delays (8months post discharge we are still waiting for a budget to be set and provider to be paid and direct payment to be agreed)

The theme of funding for community infrastructure was a recurrent theme in people's comments:

... We need an infrastructure of decent provision that isn't politically led or financially motivated i.e private finance. In my professional opinion the lack of suitable community options is the main reason people end up out of borough in expensive placements that are poor quality.

And

Increase in money available for community support to stop/avoid admission to ATUs in the first place

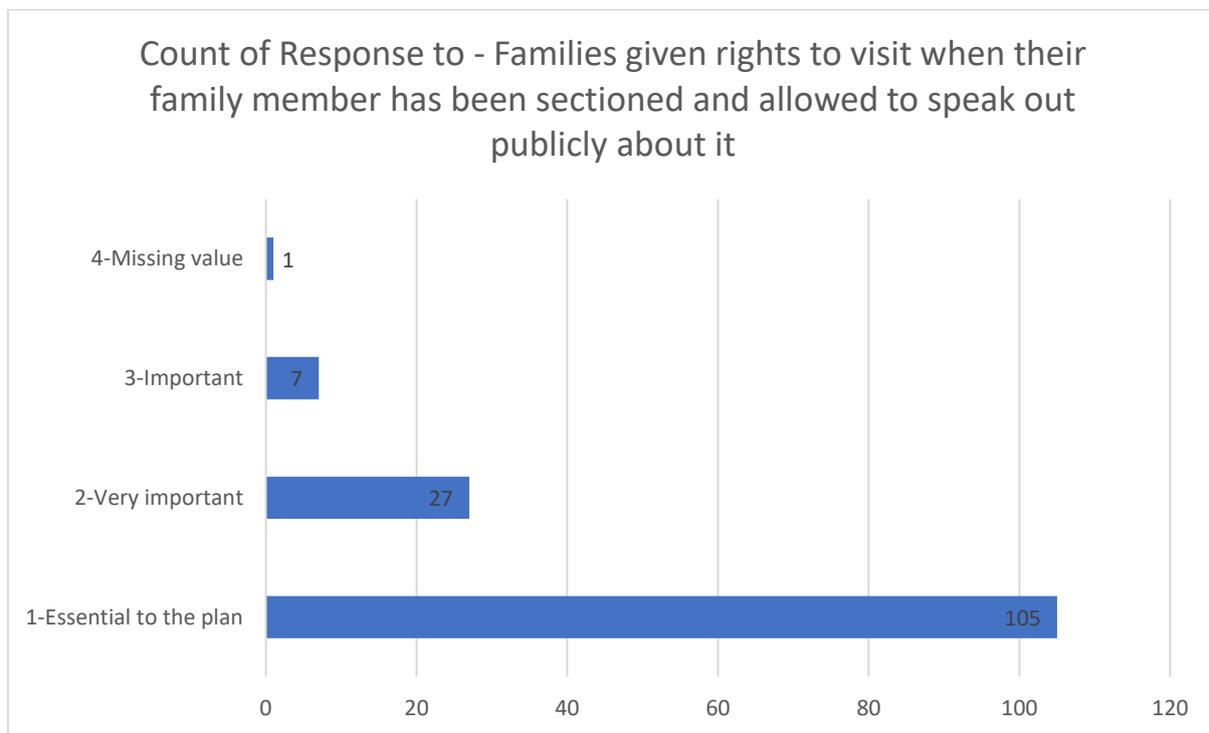
However, one respondent did not see ring fencing as the way forward

Where will the ringfencing stop? Other services are equally as important.

Nevertheless, overall it was clear that most people saw funding as integral to progress and as one person put it:

nothing happens without money

Families given rights to visit when their family member has been sectioned and allowed to speak out publicly about it.



105 or 76% of respondents indicated that it is essential for families to be given rights to visit a family member when they have been sectioned and to be allowed to speak about it publicly. If we combine the totals for “important”, “very important” and “essential” we get the unusual situation where 100% of people felt that being given this right was at least important. Although 1 respondent who made a number of challenging comments did not complete the Likert scale section.

In total 52 people commented on this proposal and of those, 45 were categorised as expansive, 4 were unconditionally supportive and interestingly 3 challenged significant aspects of the proposal despite 2 of them thinking that it was at least important for the plan.

The responses to this proposal raised a significant number of themes

- Legislative Framework
 - Advocacy, Peer advocacy
 - Individual choice
 - Allegations, Right to Privacy
 - Right to Family life
 - Consent, capacity
 - Human rights
 - MHA
 - Existing rights
 - Article 8, Court
 - Use/Mis-use of legislation
 - Balance of rights

- Safeguarding, Abuse
- Person, accountability
- Person centred approaches, early support
- Emotional support
- Transparency
- Context, abuse
- Transparency, collaboration
- Individual's consent, best interests, safeguarding
- Isolation, abuse, Transparency
- Planning
- Safe, transparency, accountability
- Education
- Recovery

One of the challenges to significant aspects of the proposal did so on the grounds of context and the possibility of abuse arguing that one size does not fit all circumstances

Depends on the reason why the person has been sectioned. Again we shouldn't have a one size fits all. For example, if the reason the person has been sectioned is because they have a has a mental health breakdown due to abuse from a family member then they should"d not have that right.

Another argued that the right to visit already existed. Another respondent argued that such rights shouldn't just be restricted to family members as this would effectively discriminate against people who don't have families to support them:

... It is important that all patients who have been sectioned have the same rights to have visitors regardless who they are. Friends and peer advocates must have the same rights as family members to visit the inpatient who is sectioned under the Mental Health Act. We need to make sure our plan does not lead to some patients having more rights than others, simply based on their visitor's relationship. It would be unfortunate if patients without any or supportive families have fewer rights to visitors than those who do...

Of the 45 expansive comments a number qualified their support for this proposal by suggesting that the right should be depend upon and individual giving their consent, or on the proviso that there are no safeguarding concerns.

Important family members can visit taking into account wishes of the person detained. We also need to bear in mind any safeguarding issues not all parents are good parents - the state should have a right to protect vulnerable people. What should happen is that the independent body is automatically alerted and ensures an IMCA or IMHA or advocate is allocated to the person.

And

Supportive family member visits are often essential to a person recovery, their visits should only be stopped if there is a safeguarding issue. Yes of course they should be able to speak out about it.

Others were unequivocal in their support for a family's right to visit their family member and ability to speak out publicly on their behalf:

People have a right to family life and that should apply were ever that person is

And

Absolutely. It is essential that families visit their loved ones often. The care in hospital is not sufficient for a person's emotional well being. It is only family that love them. Often the regime in hospitals is cold and regimental. There is no empathy or compassion. Regular and sustained family visits are absolutely paramount. Also, yes families should be able to speak out about it. If ATU's are operating as they should be and treating our loved ones correctly then they have nothing to hide so they would not have any reason to fear families speaking out. If families are prevented from speaking out this may be due to the ATU's having something to hide!

The issue of inpatient hospitals restricting access in order to hide something was another theme raised by respondents:

Openness and transparency are key. These organisations should have nothing to hide so family should be made to feel very welcome

And

No one should silence family members, ever. This is a human rights issue, a legal issue. The protection of the whole family is integral to the plan.

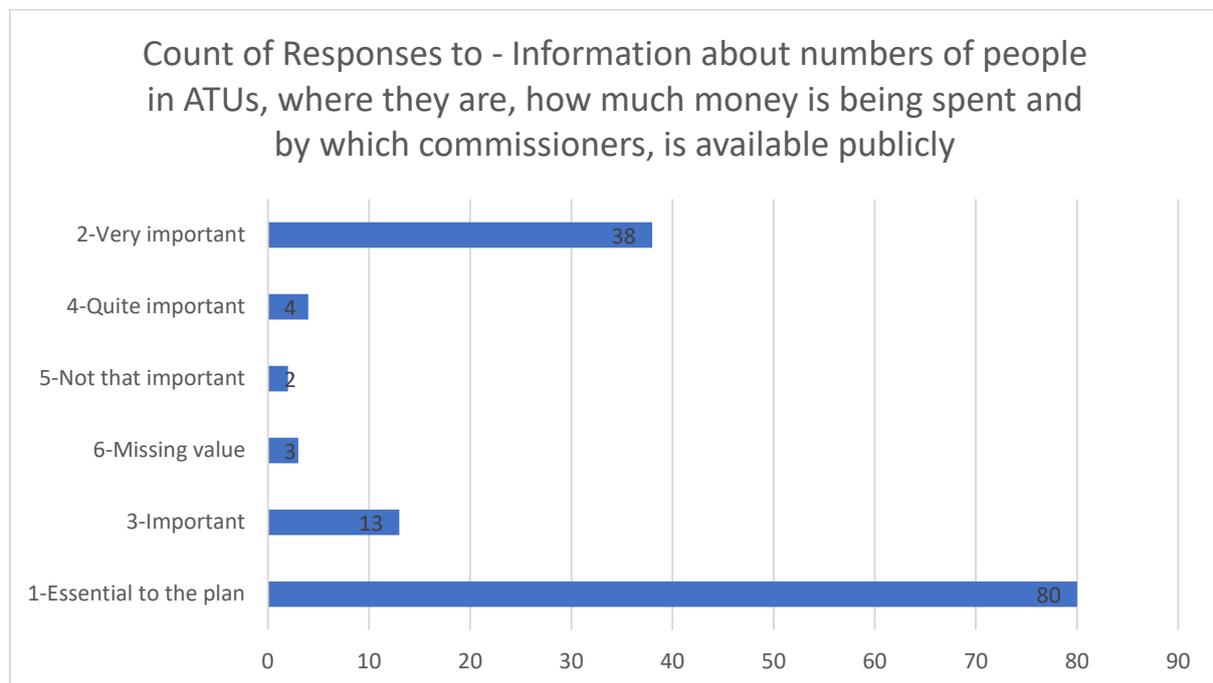
And the extent to which settings will go in order to restrict families' access was another theme:

A right to privacy and freedom of speech when talking to families. For the past 8 months mine and my daughter's contact has been cut to 3 x 15 minute phone calls per week, all on speakerphone. There are also many restrictions of topics of conversation.

One respondent raised the issue of people's rights as nearest relatives

Families have rights as nearest relatives in the MHA, families of people sectioned on 'general' MH wards aren't stopped. Families/nearest relatives need support to exercise their rights.

Information about numbers of people in ATUs, where they are, how much money is being spent and by which commissioners, is available publicly



In total 80 people or 58% indicated that they felt that this proposal is essential to the plan with 38 seeing it as very important. 40 people commented on the proposal with 8 comments that were directly supportive, 24 that are expansive and 8 that have been categorised as challenging.

Of the 24 comments that were categorised as expansive, we have been able to identify the following over-arching themes:

Best value,

Transparency

Data quality

Private Sector

Financial accountability

With the case for transparency being central to the following comment

The economic argument for community support as opposed to institutionalisation needs to be made and to date this has been difficult because of lack of transparency around the amount that is spent on inpatient placements. Data is needed at a macro level to analyse change and the impact of policy to move people out - as well as at a micro level to support arguments for individuals to be moved into new support models. I imagine that this information would be very useful to help good providers make persuasive cases for why a person should move into their support.

And

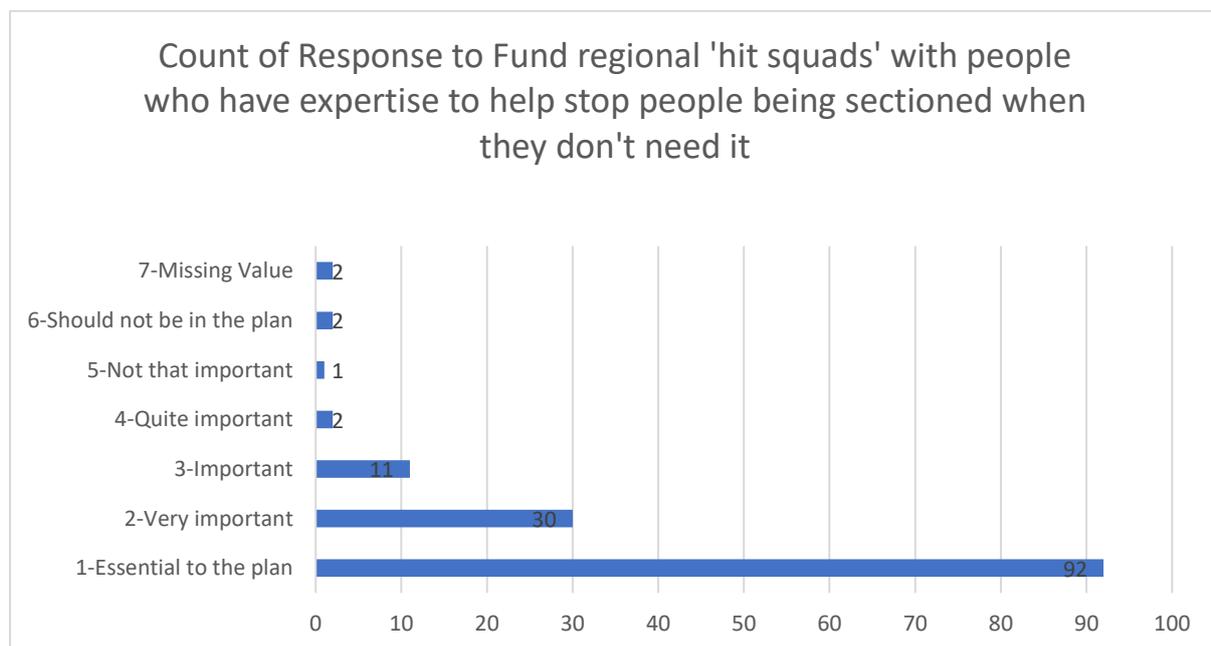
This is the only way to prove that what initially appears to be expensive personalised commissioning is actually cheaper and gives people a good life, than expensive, abusive dehumanising institutional holding pens

However, not everybody was as convinced with the need to make “*Information about numbers of people in ATUs, where they are, how much money is being spent and by which commissioners, is available publicly*”

For example

Given that most of the info is already in the minimum dataset, are you really asking for access to the finances? If so, say what you mean. It's a double edged sword, commercially sensitive (and that includes private sector and foundation trusts in NHS) but a better way would be to benchmark costs as a value comfort money and then valued added for doing what you are supposed to do. There are matrixes that can be developed that combine cost and quality and that is probably better as costs alone will not tell the whole story. Do you want someone in the cheapest service or the best? The whole system should be commissioned on quality and, if there are concerns, highly skilled ninjas that go in and kick ass :)

Fund regional 'hit squads' with people who have expertise to help stop people being sectioned when they don't need it



92 or 67% people indicated that that they felt that the idea of funding “...regional hit squads of people who have expertise to help stop people being sectioned when they don’t need it” is an essential part of the 8 Point Plan and 30% indicating that it is either very important or important and 1% of respondents indicating that they didn’t think that the proposal should be in the plan at all.

In total 54 people commented on this proposal, with 6 directly supportive comments, 39 expansive comments and 9 comments that challenge the original proposal.

The expansive comments focused on a number of over-arching themes, which included:

- Legislative framework
- Early Support
- Early intervention
- Values, outcomes, commissioning
- Lived experience
- Quality, Review
- Community Infrastructure
- Community Infrastructure, Quality
- Quality, Workforce
- Legislative Framework, Training
- Integrated working

Comments relating to the Legislative Framework included this, which emphasised the inappropriateness of sectioning autistic people and people with learning disabilities as a way of providing support:

Absolutely, of vital importance. People with autism and or a learning disability should not go into ATU's at all. Full stop. Care in the community should be looked at as an alternative and this should be actioned (not just talked about), but action taken. Kids in foster care often have needs similar to those kids who have autism yet they are not sectioned. Sectioning people with autism is wrong and inappropriate. They do not have a Psychotic illness so why do they need to be in a Psychiatric hospital and forced to take Psychotic medication to "cure them" (there is no cure for autism)!!! Being sectioned in an inappropriate settings causes harm and distress. Often people with autism become institutionalised and when they eventually get out of ATU's they have long term or even life long damage and trauma such as Post Traumatic Stress Disorder. STOP SECTIONING PEOPLE WITH AUTISM AND PEOPLE WITH LEARNING DISABILITIES. FULL STOP.

Whereas this focuses on the need to ensure that the law is being properly implemented:

Love this element the law must be implemented fairly with right to recourse where it is not. Accountability factor needs to be included.

The need to intervene early provide support is raised in this comment

Early intervention is vital to prevent the unnecessary sectioning of people, but more so families need support long before crisis is reached. Families need early diagnoses, they need early support and they need regular respite.

The role that a community's support infrastructure plays in enabling early intervention is a theme in a number of comments relating to this proposal, for example:

This common sense preventative approach is essential in minimising the lasting damage caused to people being locked away in atu's, and their families, as well as the money that would be saved long term

And

This is what is needed, I've been asking for three years to have a parachute service. Asked three agencies to be involved. Social care have put boundaries in the way excuse after excuse of why it

won't work. Yes it will. Build it and they will come is the saying, so why not build therapeutic places instead of hospitals without the section. Then back into their own homes x

And

Not just a 'hit squad' but also a safe space? - Ealing Model for Children and Young People, Durham Crashpad?

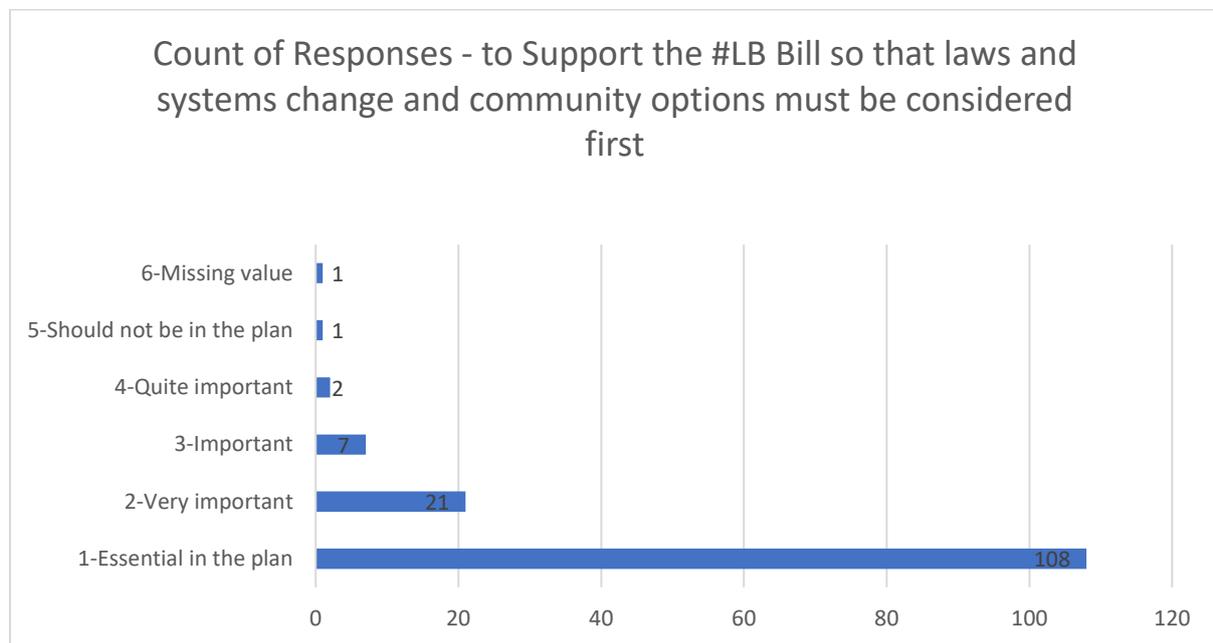
However, a number of people did have reservations about the idea. One questioned what the underlying evidence for the need for the idea is, suggesting an alternative way forward:

Do you have evidence that people have been detained under the Mental Health Act without the legal criteria being met? There are existing mechanism for overturning unlawful detention. So wondering whether what might be more helpful is access to funded legal advice and advocacy?

Another pointed out that

This should be what is standard practice - it shouldn't be a new thing it should be what professionals jobs are - don't add it - make professionals do what they are paid to

Support the #LB Bill so that laws and systems change and community options must be considered first



108 people indicated that they consider this proposal is to be essential to the Eight Point Plan, with an additional 21 people believing its inclusion to be very important. Taken together these make up 93% of all respondents. In total 28 people commented on this proposal, 5 of those comments were directly supportive, 21 were expansive and 3 challenged the proposal.

The 20 expansive comments related to the following over-arching themes:

- Legislative Framework
 - Including United Nations Convention on the Rights of Disabled People
- Community infrastructure
- Positive change
- Funding
- Human Rights
- Planning,
- Resources

Unsurprisingly themes relating to the Legislative Framework cropped up in a number of comments:

The LB Bill should be supported, but also revisited, amended and strengthened through wider direct involvement of representatives of groups described in point 2. (This started to happen, eg the meeting between Reclaiming Our Futures Alliance ROFA, People First, Steve Broach, Sarah Ryan and LB Bill people... let's get this back on track but with voices eg, Participatory Autism Research Collective, NSUN, Mental Health Resistance Network, Social Work Action Network SWAN, and the IL Strategy Group)

And

Yes, essential to permanent and meaningful change and offering full protection so that every single person is within the safety net.

As did the issue of community support but in the context of this proposal the references to community support often focused on current failings

Well again as things stand the system doesn't work, more community options looked at first for interventions would then mean only the seriously poorly people need sectioning and put in hospital !

And

YES IT IS ABSOLUTELY ESSENTIAL IN THE PLAN. People with autism and or learning disabilities should be in their communities and living at home with their families as far as possible. My son is living away from his home and his family as he has been failed by the system. He did not receive the appropriate specialist support he needed when he was at home, despite this being promised. This needs to stop. Stop sectioning our kids and make appropriate, suitable, specialist, sustainable support in the community available to them. Full stop.

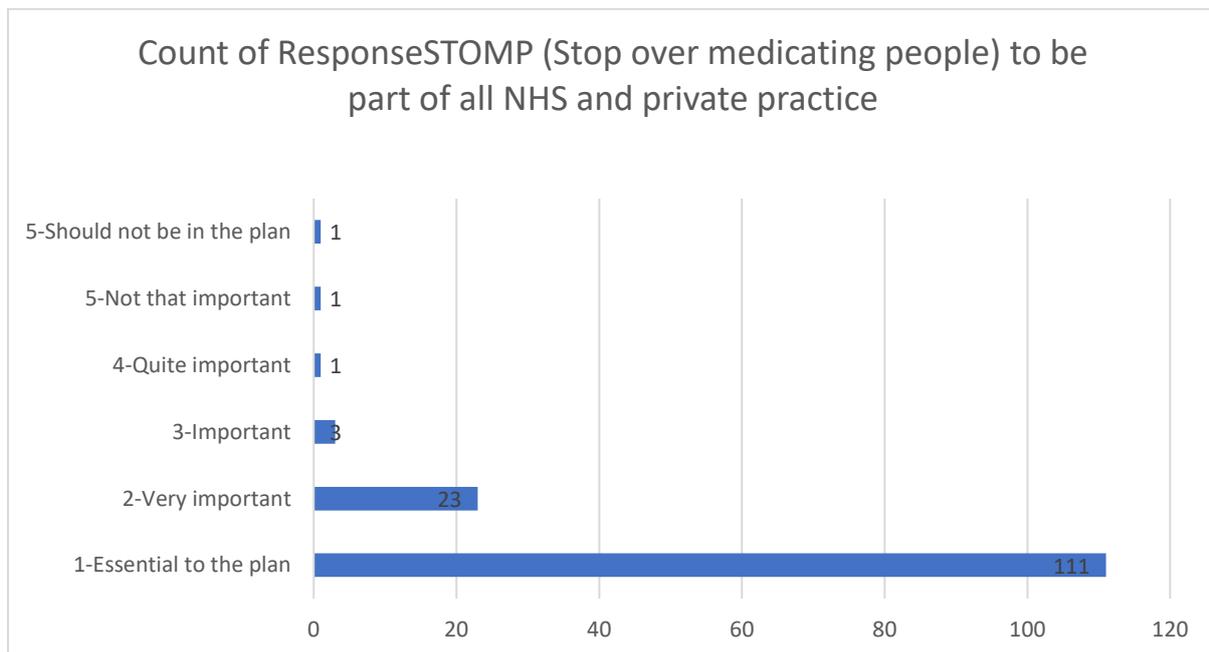
Although one respondent commented on positive changes that they had experienced:

Personally I have experienced positive change around being involved in my son's care and support needs and I ensure that his views are also considered. I am aware that this is not the case for everyone and therefore having a stronger legal system is vital to protect and enable all involved.

The three challenges to the proposal, related to it not being seen as a priority, along with the failings of community settings and parliamentary logistics;

A bill may be an uncertain way of progressing - especially when parliamentary time is so taken up with Brexit matters.

STOMP (Stop over medicating people) to be part of all NHS and private practice



In total 111 people thought that this proposal was essential to the plan, with a further 23 thinking that it is very important, meaning that in total 96% of respondents see it as at least very important. Of the people who responded to the survey 41 commented. Of those comments, 36 were expansive, 4 were directly supportive and only 1 was categorised as challenging.

The principal themes identified in the expansive responses related to:

- The regulatory and legislative framework
- Capacity and Consent
- Outcomes
- Awareness raising
- Implementation
- Medication-misuse/Abuse
- Therapeutic approaches
- Children and young people
- Social Model, workforce
- Changing culture
- Regulatory framework and enforcement
- Evidence on outcomes
- Collaboration, Person centred decision making
- Psychological theories
- Culture and values

The regulatory and legislative framework relating to the current widespread use of medication was a consistent theme in a number of responses:

*People with sufficient mental capacity to decline and who are declining should never be forcibly drugged. The European Medicines Agency, the Medicines and Health-Products Regulation Agency and its national counterpart should be forced to publish *ALL* data about and force pharmaceutical businesses to publish *ALL* data about psychiatric drugs (as these drugs can be forced upon somebody). The E. M. A. states that it has to balance the commercial confidentiality against the benefits of publishing—but where a drug is given to a (literally) captive population without the customers' consent, commercial confidentiality should 'go out of the window', in my opinion. No company or other business has the right to claim an interest in withholding information about its product from expert practitioners making and overriding private decisions on behalf of a private citizen.*

And

Crucial. Over medicating kills people, whether anti-psychotics or PRN NSAIDS. Those who prescribe drugs to be subject to stringent laws that protect people with a learning disability.

And

Laws should be drastically changed for all people

With the failings of the current regulatory system linked to the mis-use of medication

Behaviours that challenge should stop being seen as a MH problem. Anti psychotic meds should not be used routinely and perhaps where considered for people with LD we should use the same system as someone detained who disagrees with meds - SOAD - second opinion appointed doctor should always be used for a second opinion.

And

Absolutely! the misuse of medication not only shortens peoples lifes, it also supports a the failure to provide appropriate care. It's ok not to meet a persons needs because when their behaviour deteriorates as a consequence we can just sedate them....

And

Inappropriate over-medication is an abuse.

A number of respondent's comments cited STOMP and STAMP as an important initiative in the struggle to change culture and values.

Everyone should be involved with STOMP. Keep questioning why are they on that medication, is it needed?

The idea of STOMP really is about RESPECT

And whilst one respondent identified STOMP as a very important initiative they pointed out that for their family member it had not been without its problems:

This is a big issue for our family my brother started getting severe anxiety and meltdowns after being transferred to a new drug under stomp which did not help him and transitioning back to the old drugs has taken over a year

Interestingly one respondent wondered whether this type of initiative might be extended:

...to include other forms of unnecessary or inappropriate treatments that may not involve medication. Too much focus on self-behavioural analysis, normalisation, too much therapy or whatever could equally be damaging for patients.

Have you got other points that you think should be included?

There were a broad range of suggestions regarding what other points people felt should be in the plan, relating to a broad range of themes;

1. Early intervention
2. Legislative Framework
3. Workforce
4. Community Infrastructure
5. Experts by Experience
6. Rights and advocacy
7. Family support
8. Community Awareness
9. Human rights advocacy
10. CTRs - properly enforced
11. Quality
12. Physical Health
13. MHA
14. Community infrastructure and Early intervention
15. State has to take responsibility for Human Rights and lack of community support.
16. MHA Compliance
17. Whole system improvements
18. Support rights based practice
19. Human rights enforcement
20. Respect Training
21. Involvement and governance

At least two called for a strengthening of Care and Treatment Reviews:

CTR follow ups and time scales adhered to and social care MUST support families in the community for discharge to happen. Social care are the worst culprits

And

The Care-&-Treatment Review should have legally-enshrined powers. None the less, the 'elephant in the room' is the abolition of the 'Mental Health Act'—if patients could 'vote with their feet', all the big bad guys would go out of business overnight.

This call for the abolition of the MHA, or least it's dis-application to people with learning disabilities and autistic people was a re-current theme in people's comments:

I can't stress enough how much the Mental Health Act is the key for large numbers of people who have their lives ruined by ATUs - part of the problem here is the scale of the issue and tackling it in one way is not going to work. It's about annexing the flow to stem the tide, and then the above can clear the backlog.

Although for another the issue wasn't so much the abolition of the Mental Health Act as much as its proper implementation and enforcement:

More work needs to be done to ensure compliance of the mental health act by all professionals who have to be compliant. It's like the mental health act code of practice doesn't exist in ATU's. Non compliance of the law is illegal and more should be being done to those who break the law. Responsible clinicians should be accountable under the legislation, not talk their way out of it in enquiries etc. Their practice vs the code is never questioned and that's what it's there for so has to be included in enquiries.

One respondent called for more involvement from Experts by Experience, and another wanted greater focus on human rights and access to independent advocacy and support for self-advocates. A number argued that there should be a focus on the enforcement of Human Rights legislation.

Is there scope for legal challenge(s) for breaches of human rights legislation? NHSE to fund a national training programme for families of autistic children and/or children with a learning disability on crisis prevention, understanding CEMTs and understanding families and children's rights.

And

human rights lawyers should regularly visit people & review their rights are intact. There should be human rights tribunals instead of mental health tribunals

And

The state needs to take responsibility that the breaches of human right abuse has occurred due to the contract culture. Fact the community as care not been supported . Failure to respond by being able to stop finance of big corporate bodies etc

Another called for awareness training across the community:

All authority figures that are involved in sending our kids to ATU's e.g Police, LA's, GP's should all have better training regarding how to treat and support people with autism and or learning disabilities. Currently these authority figures are part of the problem. Make them part of the solution instead with better training and constant monitoring and assessment to ensure they are meeting the needs of people with autism and or learning disabilities and that they are no longer part of the problem.

One of the most recurrent themes throughout has been the call for increased investment in community support and the need to do work to prevent people from having to go into inpatient hospitals.

Local services need to increase and preventative services and approaches used

So how should we revise our 8 Point Plan- What should good look like?

In answering these questions, we think it's worth looking at our consultation results in the context of a number of other reports and publications relating to support for people at risk of being detained in inpatient hospitals. The first is the revised Mansell report (Mansell, J.L. 2007) published in 2007, and the second is *Building the Right Support* (DoH,2015). The reason for doing this is straight forward, most of the themes and issues relating to supporting people with learning disabilities and autistic people who are at risk of having to go into an inpatient hospital, have been known about for years. Many of the issues that people have raised in this consultation relate to themes and policy proposals that have been looked at before and that are particularly evident in Mansell's Report and *Building the Right Support*. So often when most of us look at social policy challenges we like to imagine that we are the first people to have to deal with these issues, when in truth we rarely are.

In his report - *Services for people with Learning Disabilities and Challenging Behaviour or Mental Health Needs: Report of a Project Group* – Mansell identifies a number of key recommendations which in the light of the responses to our 8 Point Plan consultation process are worth look at again.

Firstly, Mansell identifies the following as one the project's three aims:

1. *Better use of investment is required to achieve two aims:*
 - *to develop and expand the capacity of local services for people with learning disabilities to understand and respond to challenging behaviour*
 - *to provide specialist services locally which can support good mainstream practice as well as directly serve a small number of people with the most challenging needs*

The importance of this aim or objective is also reflected in *Building the Right Support* which cites a requirement for Transforming Care Partnerships to develop a National Service Model that will respond to and be able to meet the needs of this diverse group of people in the communities in which they live.

The National Service Model

1. People should be supported to have a good and meaningful everyday life - through access to activities and services such as early years services, education, employment, social and sports/leisure; and support to develop and maintain good relationships.
2. Care and support should be person-centred, planned, proactive and coordinated – with early intervention and preventative support based on sophisticated risk stratification of the local population, person-centred care and support plans, and local care and support navigators/keyworkers to coordinate services set out in the care and support plan.
3. People should have choice and control over how their health and care needs are met – with information about care and support in formats people can understand, the expansion of personal budgets, personal health budgets and integrated personal budgets, and strong independent advocacy.

4. People with a learning disability and/or autism should be supported to live in the community with support from and for their families/carers as well as paid support and care staff – with training made available for families/carers, support and respite for families/carers, alternative short term accommodation for people to use briefly in a time of crisis, and paid care and support staff trained and experienced in supporting people who display behaviour that challenges.

5. People should have a choice about where and with whom they live – with a choice of housing including small-scale supported living, and the offer of settled accommodation.

6. People should get good care and support from mainstream NHS services, using NICE guidelines and quality standards – with Annual Health Checks for all those over the age of 14, Health Action Plans, Hospital Passports where appropriate, liaison workers in universal services to help them meet the needs of patients with a learning disability and/or autism, and schemes to ensure universal services are meeting the needs of people with a learning disability and/or autism (such as quality checker schemes and use of the Green Light Toolkit).

7. People with a learning disability and/or autism should be able to access specialist health and social care support in the community – via integrated specialist multi-disciplinary health and social care teams, with that support available on an intensive 24/7 basis when necessary.

8. When necessary, people should be able to get support to stay out of trouble – with reasonable adjustments made to universal services aimed at reducing or preventing anti-social or 'offending' behaviour, liaison and diversion schemes in the criminal justice system, and a community forensic health and care function to support people who may pose a risk to others in the community.

9. When necessary, when their health needs cannot be met in the community, they should be able to access high-quality assessment and treatment in a hospital setting, staying no longer than they need to, with pre-admission checks to ensure hospital care is the right solution and discharge planning starting from the point of admission or before.

Building the Right Support, 2015, p.25

It is clear from the responses to our consultation, a good number of which focused on the need for improved community infrastructure, that the nine principles of the National Service Model are not a reality and that for many people the objective set out by Mansell of developing and expanding “*the capacity of local services for people with learning disabilities to understand and respond to challenging behaviour*” has not been met and neither is 24 hour specialist or crisis support available.

As part of Mansell’s second aim he states:

...At service system level, value for money should be demonstrated by a low number of placement breakdowns and of out-of-area placements. Low-value high-cost services should be replaced by better alternatives...

The responses to a number of proposals indicate that the themes of value for money and importantly concerns about transparency and the cost of “*Low-value high cost services*” remain and that Mansell’s hope for better use of investment remains unmet.

Other themes that are reflected in the results of our consultation and Mansell’s aims are those of *rights, inclusion, independence and choice* and the support evidenced in our proposal to revisit the LB Bill and a great many of the responses to the other proposals indicate that the need to strengthen people’s rights and for changes to the legislative framework remains. For some it means abolishing the Mental Health Act for others it means giving statutory force to Care and Treatment Reviews.

But the current situation doesn’t just require legislative change, which will be challenging in the current political climate and which has to be seen as a medium term objective, it also requires the proper enforcement of the rights that people already have. As one of our respondents stated:

More work needs to be done to ensure compliance of the mental health act by all professionals who have to be compliant. It’s like the mental health act code of practice doesn’t exist in ATU’s. Non compliance of the law is illegal and more should be being done to those who break the law. Responsible clinicians should be accountable under the legislation, not talk their way out of it in enquiries etc. Their practice vs the code is never questioned and that’s what it’s there for so has to be included in enquiries.

And the themes of accountability and of properly enforcing the law that already exists represents a significant concern for many of our respondents and a way in which immediate progress and improvements to the lived rights and well-being of people with learning disabilities and autistic people can be made.

- Are local authorities meeting their responsibilities under Part 1 of the 2014 Care Act?
- Are local authorities, NHS Commissioners and providers and housing services working together to provide person centred support in such a way that it prevents their needs from increasing?
- Is the Mental Capacity Act being properly enforced are the views and knowledge of the people who know a person best being listened to and incorporated into Best Interests decision making?
- Is the support and treatment being provide to an individual being provided in accordance with the five over-arching principles of the Mental Health Act;

Which, in the light of recent events and some of the responses to our consultation, are worth reminding ourselves of in full.

The five overarching principles are:

Least restrictive option and maximising independence

Where it is possible to treat a patient safely and lawfully without detaining them under the Act, the patient should not be detained. Wherever possible a patient's independence should be encouraged and supported with a focus on promoting recovery wherever possible.

Empowerment and involvement

Patients should be fully involved in decisions about care, support and treatment. The views of families, carers and others, if appropriate, should be fully considered when taking decisions. Where decisions are taken which are contradictory to views expressed, professionals should explain the reasons for this.

Respect and dignity

Patients, their families and carers should be treated with respect and dignity and listened to by professionals.

Purpose and effectiveness

Decisions about care and treatment should be appropriate to the patient, with clear therapeutic aims, promote recovery and should be performed to current national guidelines and/or current, available best practice guidelines.

Efficiency and equity

Providers, commissioners and other relevant organisations should work together to ensure that the quality of commissioning and provision of mental healthcare services are of high quality and are given equal priority to physical health and social care services. All relevant services should work together to facilitate timely, safe and supportive discharge from detention.

MHA Code of Practice, 2015, p.22

And then of course, the Human Rights Act which in Section 6 paragraph 1 states:

It is unlawful for a public authority to act in a way which is incompatible with a Convention right.

So, to return to the first part of the question with which this section of the report opened, how should we amend the 8 Point Plan in the light of this consultation?

Revising the Eight Point Plan

Prior to the opening of this consultation our 8 Point Plan consisted of the following proposals:

1. A review and plan for everyone in an Assessment and Treatment Unit (ATU) to get community support within 12 months.
2. An independent body led by people with learning disabilities, autistic people, families and lawyers that has power to monitor and direct commissioners and can remove power from commissioners that are failing.

3. Ring fencing money just for community services and the transition from Assessment and Treatment Units.
4. Families being given rights to visit when their family member has been detained under Section of the Mental Health Act 1983 and being allowed to speak out publicly about it.
5. Information about the numbers of people in ATUs, where they are, how much money is being spent and by which commissioners, is made publicly available.
6. Funding of regional 'hit squads' with people who have expertise to help stop people being detained under the Mental Health Act.
7. Support for the proposals of the systems change to safeguard people's right to have community alternatives to a hospital or care Disabled People (Community Inclusion) Bill 2015, also known as "the #LBBill" so that laws and home admission considered first.
8. STOMP (Stop over medicating people) to be part of all NHS and private health care practice.

In the light of people's comments and responses we would suggest making the following amendments to the Eight Point Plan. The changes incorporate people's overwhelming support for the proposals set out in the original 8 Point Plan but create a new one and reframe 6 of them to take account of existing powers and legislation. The eighth, concentrates the longer term need for legislative change, into a single proposal. In this way the plan can deal with the challenge that its proposals aren't deliverable under current legislation, whilst at the same time still campaign for the legislative change that people need.

1. A review and plan for everyone in an in-patient hospital to get community support within 12 months or sooner;
 - a. Including a strengthening and greater focus on the use of CTRs and CETRs;
2. Steps should be taken by all responsible bodies to ensure that individual's rights under existing legislation are being met and that public authorities and publicly funded bodies are meeting their statutory responsibilities;
3. The establishment of an independent body led by people with learning disabilities, autistic people, families, lawyers and representatives of key stakeholder organisations, that has the remit to monitor and hold responsible bodies to account, in accordance with the requirements of existing legislation.
4. Increased funding and investment in community services, preventative support and in the transition from inpatient hospitals.
 - a. Including the funding of specialist teams (Hit Squads) with people who have expertise to help stop people being detained under the Mental Health Act.
5. Families' and friends' right to visit, when a family member or friend has been detained under the Mental Health Act 1983, being properly enforced and work undertaken to prevent the misuse of current legislation by providers and commissioners in inappropriately silencing and gagging families, friends and advocates;
 - a. Including the right to speak publicly about an individual's detention in accordance with current legislation where this is with their consent or in their best interests;
6. Information and transparency about local area and national plans to support and meet the needs of people with learning disabilities and autistic people, the numbers of people in inpatient hospitals, where they are, how much money is being spent and by which commissioners.
7. STOMP (Stop over medicating people) to be part of all NHS and private health care practice.
8. In the longer-term, support legislative change to strengthen people's right to independent living and a life free from the threat of detention, with community alternatives to hospital care:

- a. Drawing on the principles outlined in the Draft Disabled People (Community Inclusion) Bill 2015, also known as “the #LBBill” so that laws and home admission considered first;
- b. The United Nation’s Convention on the Rights of People with Disabilities;
- c. Giving CTRs and CETRs statutory powers;
- d. Including strengthened rights to advocacy and independent support for people without families or whose families are not involved in their lives;
- e. Rights to peer advocacy and visits from friends and people who know them well;
- f. And strengthened rights for families whose family members have been detained.

So, what does good look like?

Another way of phrasing this question might be to ask, what is it that we are trying to achieve with our Revised Eight Point Plan? The 8 Point Plan’s underlying objectives are that people with learning disabilities and autistic people should have:

A rights-based life

In a recent blog the retiring Deputy Chief Inspector of Hospitals for the CQC, Dr Paul Lelliott stated:

A significant number of people with a learning disability or autism are admitted to a hospital because the health, care and education system has failed to support them to live fulfilling lives in their own home. Once there, they may become stuck in the hospital because of the absence of any alternative. Recent events have highlighted the risk that these hospitals may become closed and punitive institutions.

Paul Lelliott, 2019

This recognition on the part of Paul Lelliott supports our position that a significant number of people are being deprived of their right to an ordinary life because the systems and support that they and their families need, are not available at the time at which they are needed. The fact that so many people are detained in inpatient hospitals, far from their family and friends, is a measure of the extent to which the system is failing to protect people’s rights, in particular The Right to Liberty, The Right to Respect for Private and Family Life and The Prohibition from Torture and Inhuman Treatment.

Meeting the needs of people with learning disabilities and autistic people in their own communities is the foundation stone of a rights-based life. It should also be foundation stone of what a solution and way forward should look like.

A rights-based approach to community support

Based on a flexible and personalised community infrastructure, capable of supporting individuals in their home and with community-based crisis support. Support that draws on the aims of Mansell and the principles of Building the Right Support. Mansell’s report, also goes into significant detail on what services for autistic people and people with learning disabilities and behaviour that challenges should look like and it is important to recognise the importance of early intervention and preventative work.

Mansell illustrates that the need for effective services doesn’t just arise out of the needs of people in crisis, emphasising as well the important role that good quality support can play in preventing the development of behaviour that challenges in the first place. Mansell’s committee takes the view that

for some people, challenging behaviour can become a life-long behavioural option once it has become established - recognising that

There will always be a large pool of people who present some challenging behaviour, which can be better or worse depending on how well services support them.

*A proportion of this 'at risk' population at any one time present an exceptional challenge to services because of their behaviour. Estimates depend on definitions, but over the whole country it is likely that about 24 adults with a learning disability per 100,000 total population present a serious challenge at one time. This means that there are over 12,000 people with learning disabilities in England whose behaviour presents a serious challenge at one time. This includes people with mild as well as severe learning disability. A few of these people will present such a challenge more or less all the time and will become well-known to local services (as well as, in some cases, other agencies like the police and housing departments); **but many people will move into and out of this group depending both on changes in their characteristics and on how well services meet their needs over time.***

Mansell Report, p. 8 -9 (our emphasis)

It is this point that we want to focus on – that for a number of people with challenging behaviour their ability to live in the community is dependent upon the quality of the support that they receive throughout their lives and that the earlier that good quality intervention takes place the better. And it is reasonable to assume that the number of people in inpatient hospitals is at least in part a reflection of the quality of the support that a child and their family have received throughout childhood, as well as a reflection of the quality of the support that is available to them as adults. Mansell points out that:

preventing the development and worsening of challenging behaviour is a priority because of the costs (to the individual, family and society) of problems escalating or becoming ingrained

Recent increases in the number of children and young people going into inpatient hospitals, indicate that Transforming Care hasn't led to improved early intervention and the development of preventative support. And that hopes to improve transition support for young people with special educational needs, that were an integral part of the SEND Reforms, do not appear to have been effective for this group of young people.

We would therefore expect to see a greater emphasis on prevention and early intervention and in getting the transition from children's to adult services right, as well as the current requirement in the NHS Long Term Plan to develop access to specialist support services. But as one of the respondents stated these developments have to take place in the context of accessible and welcoming communities

We need a plan to phase out ATUs all together and to have mental health support services to be made available in the person's own home – where necessary the "hospital" service needs to come to person's own home. We need transfer of funding from ATUs into creating new homes and providing properly funded care packages with skilled staff to support former patients to be fully engaged in activities within their communities. We need welcoming communities with activities that are inclusive of all. Need to deal with social isolation and preventing people from victims of mate crimes as they have no real and meaningful relationships with others...

Transparency and accountability

The lack of progress achieved by Transforming Care that is evident in the responses to our consultation and in our recently published report, *Is Care Transformed? A Review of Transforming Care in England* indicates that a number of factors that have played a role. However, from the relative lack of progress and allowing for local differences in access to transformation funding, it is apparent that there has been significant variation in the commitment of local areas to delivering Transforming Care's objectives.

An interesting observation in the Mansell Report is made on the role that local commissioners and providers play in relation to the support that is available for people locally for people with behaviour that challenges. A submission to the Mansell Report Committee grouped managers into three categories, depending on their approach to how they developed services for people with behaviour that can be challenging.

- *'Removers' do not want to develop locally the competence to serve people whose behaviour presents a challenge (perhaps because they perceive the task as too difficult, or not worth the effort). They seek instead to place people who cannot be served locally in out-of-area residential placements, often at considerable expense.*
- *'Containers' do seek to provide local services (perhaps because of the cost of out of-area placements) but seek only to contain people in low-cost (and therefore poorly-staffed) settings.*
- *'Developers' seek to provide local services which really do address individual needs, and therefore give higher priority to funding services which, with more staff and more training and management input, are more expensive than ordinary community services.*

** By George Gaskell and Julie Dockrell of the London School of Economics; the classification presented here is a modified version of that they proposed.*

Looked at in these terms, the variation in the delivery of Building the Right Support's indicates that amongst other factors insufficient progress has been made in turning "Removers" and "Containers" into "Developers". It also supports the position we adopted in "A Trade in People" (Brown, James & Hatton 2017) in which we argued that:

...inpatient rates are being influenced by the decisions of healthcare entrepreneurs to locate in areas where house prices are lower and that once there, the length of their stay in hospital will be influenced by the care infrastructure that is in place. Namely the numbers of people who are inpatients, the number of CQC registered settings and the number of s117/CHC packages of care.

If considered in conjunction with the experiences of people with learning disabilities and their families and the content of a number of the Transforming Care Plans, it is clear to us that the way in which the healthcare economy has been encouraged to develop by recent governments turns people into commodities and liabilities. For local authorities and CCGs they are liabilities that they have often sought to export to other areas and for independent hospitals they are a commodity and source of millions of pounds of income and profit.

Our position on this is clear, we believe that areas that see the "export" or "Removal" of people with learning disabilities and autistic people as a long-term policy option are failing in their responsibilities to this community. It is also clear from the responses to our consultation that the failure to properly implement policy extends beyond Transforming Care. And evidence of a failure to properly implement and enforce existing legislation is a theme in a number of the responses.

If this situation is ever going to change, it is essential that steps are taken to promote transparency and accountability, in order to prevent areas that are performing poorly from hiding their failure to support the human rights of people with learning disabilities and autistic people. It is also important that areas, that have developed transformative services, are able to share their good practice and the details of their progress, in a way that is timely and helpful to other organisations and care systems.

We would therefore argue that a rights-based approach would require the full and proper implementation of policy initiatives and the enforcement of existing legislation in order to defend an individual's rights under that legislation. This would include having access crisis support that more often reflects the principles set out in the MHA Code of Practice 2015.

It would also require greater accountability at the level of the individual with enhanced CTRs and CETR holders holding people to account for their actions in support of an individual supported by *“an independent body led by people with learning disabilities, autistic people, families, lawyers and representatives of key stakeholder organisations, that has the remit to monitor and hold responsible bodies to account, in accordance with the requirements of existing legislation”* operating at a local and strategic level.

Long term changes to the legislative framework

Whilst in the short term we believe that much can be achieved by rigorously implementing and enforcing the legislation that currently in place, in the longer term steps need to be taken to amend the current legislative framework so that it is better able to support the right of people with learning disabilities and autistic people to live independent and rights based lives.

Leadership

Ultimately none of what we hope for will happen without leadership. And that leadership has to be found at all levels; from politicians to commissioners and social workers and families. The successes of Transforming Care, and there have been many, have come from organisations and individuals who have taken responsibility for their role in the well-being of an individual. People and organisations who have worked together and who have done what it takes to get things right for that person. But systemically things will only improve if the political will to defend the human rights of people with learning disabilities and autistic people is in place. We believe that the 8 Point Plan is something that could help the government to do that.

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