MUSLIM WOMEN'S NETWORK UK
RESPONSE TO DEPARTMENT OF HEALTH CONSULTATION:

No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions

29th May 2015

Introduction

1. Muslim Women's Network was formally established in 2003 with the support of the Women's National Commission (WNC), to give independent advice to government on issues relating to Muslim women and public policy. In 2007, Muslim Women's Network decided to establish itself as an independent organisation to ensure its autonomy from Government. The group was renamed 'Muslim Women's Network UK' (MWNUK) and became a Community Interest Company in 2008. In December 2013 it formally became a registered charity[1].

2. MWNUK's aim is to gather and share information relevant to the lives of Muslim women and girls in order to influence policy and public attitudes, to raise the profile of issues of concern to Muslim women and to strengthen Muslim women's ability to bring about effective changes in their lives.

3. At the time of writing, MWNUK has a membership of over 600 that includes individuals and organisations with a collective reach of tens of thousands of women. Our membership is diverse in terms of ethnicity, age, religious backgrounds, lifestyles, sexual orientation and geographic location. Members are also from a range of employment sectors including: higher and further education; voluntary sector and support services including services workers; health and legal professionals; the police and criminal justice sectors; and local and central government. Our members are mainly Muslim women living and working in the UK while our non-Muslim members work with or on behalf of Muslim women.

4. Changing attitudes to mental health matters is one of our six current priority areas and forms a part of our overall commitment to promoting equality, diversity and the social inclusion of all individuals in society. MWNUK are aware of the stigma and misconceptions that surround mental health issues not only within the Black & Minority Ethnic (BME) and Muslim community but across all communities. Irrespective of gender, faith or ethnicity, individuals suffering from various mental health issues are faced with a lack of understanding of their situation as well as inadequate care and support which does not take their needs into account. Individuals can feel further disabled and infantilized rather than enabled and empowered. Such situations are not limited to mental health matters however and extend to various other health issues

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[1] Charity Registration Number: 1155092

including autism, learning disabilities, downs syndrome, multiple sclerosis and parkinson's disease to name a few. In turn, MWNUK is committed to tackling the issues in respect of all health related matters in a bid to empower individuals to live a better quality of life.

5. In turn we have carried out a range of activities to further our aims from arranging events and workshops to raise awareness of mental health matters, to liaising with key stakeholder organisations and responding to a CPS consultation on policing and mental health.[2] In MWNUK's 2013 report "Unheard voices"[3], it was highlighted how young Asian women and girls with learning disabilities or mental health matters were particularly vulnerable and targeted by perpetrators for sexual exploitation. MWNUK have also supported world autism day and have been working on the promotion of organ donation to combat the shortage of organ donors within BME communities. Most importantly, we launched the Muslim Women's Network Helpline on 14th January 2015 to provide support and guidance to service users; volunteers have been provided with training on supporting individuals with mental health matters and learning disabilities and hold awareness of other physical health issues. We will be undertaking further work throughout 2015 in the hope of effecting change.

6. In order to ensure the inclusion of a diverse range of voices in connection with this Consultation, we sought the views of our members in relation to the proposals and where relevant, have included comments received.

Response

7. MWNUK's constant concern has been that whilst a lack of understanding of autism, learning disabilities and mental health matters is prevalent within all communities irrespective of faith and ethnicity, there are particular hurdles and barriers faced by those affected within the Muslim and BME communities that need to be considered and addressed by the Department of Health when considering key changes to care.

8. There have been various instances of failures in approach and understanding by various individuals and organisations including the police and medical profession when dealing with sufferers, which has caused more harm than good. In turn, better training, guidance and most importantly awareness from a faith and cultural perspective is required together with a multi-agency approach if issues are to be addressed in an effective manner.

9. We welcome the comments by Norman Lamb in the Foreward of the Consultation: *"The principle of expertise by lived experience should be absolutely core to the design of the system. People should be able to take charge of decisions about their care with personal budgets. Services must listen to the*

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[2] http://www.mwnuk.co.uk//go_files/resources/947835-MWNUK%20Mental%20Health%20Written%20Evidence.pdf

[3] http://www.mwnuk.co.uk/go_files/resources/UnheardVoices.pdf

people they are there to serve. All people have a right to be in control of their own lives as far as possible". MWNUK very much echo these sentiments and we ourselves are informed by the voices of Muslim women and girls by gathering evidence of their lived experiences. We in turn hope that through our Response we are able to assist in ensuring that a system that is fit for purpose and takes into account all individualities can be achieved.

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

10. In order to properly cater for the needs of an individual it is vital that all organisations and bodies involved work collectively and in unison, with the promotion of individual wellbeing being the guiding principle in treatment and care. If local authorities and NHS commissioners are to work together for the betterment of individuals and a fit for purpose system is to be achieved then it should be a given that they all share the same aims. To have it otherwise will lead to fragmented treatment and care which may do more harm than good as quite simply, all parties will be working in different directions and are likely to also hinder each others progress as well as that of the individual.

11. As stated at para. 1.7 of the Consultation, it is important that there is a shared commissioning framework across health and social care that is centred around the person. Indeed such a vision should not be limited to only local authorities or the NHS but to all stakeholder organisations that may become involved in the lives of individuals. In turn we believe that NHS commissioners should share new local authority duties around promoting individual wellbeing.

In making decisions on living arrangements (whether suitable accommodation or inpatient stays both) 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? If so, what might the appropriate length of inpatient stay be where this should apply to the NHS? What are your views on how this might impact on LAs and the NHS?

12. We wholeheartedly agree with the view that factors which support inclusion in the community be taken into account when making decisions on living arrangements, and in particular when considering suitable accommodation. Ensuring that an individual is placed in an environment by which they feel comfortable and have a positive support network available enables the individuals to empower themselves towards their road to recovery and/or to live their lives in the best possible manner not withstanding their health matters or learning difficulties. It is vital that individuals are not isolated from the

community and treated as "outcasts"; not only does this impact on the individuals wellbeing but also contributes to the lack of understanding and myths prevalent within communities. In other words, by isolating sufferers of mental health issues it portrays a negative image to the wider community who, intentionally or unintentionally, then continue the myths.

13. We in turn agree with the points raised at para. 1.1 of the Consultation: "Disabled people including those with learning disability, autism or mental health needs, have the same rights as everyone else". Individuals should remain a part of their family and community with access to education and employment opportunities and all other resources and services essential to achieve a good quality of life. It is especially important to aim at empowering individuals rather than to disempower; just because someone may have mental health issues does not mean that they must be isolated and "locked away" in a room for the rest of their lives.

14. However, due consideration also needs to be given to other factors that may not always be obvious when considering inclusion in the community; it is for this reason that we propose proper training and guidance be implemented to ensure that all organisations and bodies involved in providing care and treatment are aware of the individualities and diverse range of issues that may be prevalent.

15. One key issue to consider is the stigma prevalent within BME communities in respect of mental health issues, autism and learning disabilities; when these matters become known the individuals and their family are immediately ostracized by the community. Due to a lack of understanding of mental health matters and the prejudices held, those with such issues are immediately considered in the most negative light and believed to be "out of mind" and "out of control"; they and their family members are talked about in a negative manner and isolated. In one case study, a teenage child was diagnosed with bi-polar disorder; once this became known people stopped visiting the family or inviting them to events. By their account they were treated as if the individual was suffering from a contagious disease. It is vital therefore to take these matters into account; merely placing them within an environment where they are with family or friends will not in itself allow social inclusion. Care needs to be taken to ensure that individuals are in a truly supportive and inclusive environment.

16. It is also important to note that in some circumstances the mental health issues can become known partly due to the location chosen during a period of inpatient stay (for example, if it is in the same area as where the individual lives) and a lack of regard shown by professionals during home visits (for example, announcing the reason for their visit whilst other guests may be in attendance). Although we appreciate that the choice of location is likely to have been made with the best of intentions, such as making it easier for family members to travel

to visit during inpatient stay, unfortunately this can sometimes worsen a situation rather than make it better. In one example, a mother has informed MWNUK that she would take a longer route to visit her child even though the unit was down the road merely so that she can avoid being recognised by anyone she knew. On the second occasion that her child needed to be taken into hospital due to their mental health issues she asked that for the child to be kept at a location much further away even though it would mean over an hours journey and travel costs would cause financial detriment. We ask therefore that these matters are taken into account particularly in regard to inpatient stays so as to both assist the individuals and their families to ensure inclusion in the community without causing any detriment.

17. In respect of visits to the home, it needs to be understood that the mere fact that a visitor is present at an individual’s home does not mean that they are aware of the issues faced or indeed that they would be supportive. It is important that such factors are taken into account in order to allow true empowerment and inclusion in the community.

18. Furthermore, merely having an individual near family or friends should not in itself be seen as sufficient to allow inclusion in the community. There are individuals who believe autism and mental health matters are linked to magic or other supernatural causes and believe the solution or “cure” is exorcism rather than medical treatment and care. We agree with the comments included at para 1.11 of the Consultation that the default attitude and cultural approach should be that statutory bodies make effort to do what is in line with people’s wishes and recognize the importance of people being in their own home or community and strongly believe that this needs to be aimed for as far as possible. However it is also important that a proper assessment takes place to ensure that the correct support mechanisms are available. To do so, it is vital that all key stakeholder organisations hold the required awareness to be able to evaluate the quality and quantity of social relationships so as to allow “real” inclusion.

19. That said, we hope that the above matters are not construed to suggest that those of the Muslim and BME community are not kept within the community. Rather, we believe it is even more important for such individuals to maintain their self-identity and remain able to continue their lives in the manner they wish in order to combat the ostracization and disempowerment they would otherwise face. In fact by highlighting the “normality” of mental health, autism and learning disabilities and making clear that life does not “end” with such conditions, we hope that this will in turn dispel myths and combat the stigma prevalent in all communities. What we do ask for however is that the needs of the individual are taken into account; it is after all their lives that we are all aiming to assist.

We think that local authorities and the NHS could have to think about how to ensure enough community based support and treatment services (for example, for people with learning disability or autism most at risk of going into hospital). What do you think of this idea? What steps could we take to ensure such a duty is as effective a possible? What is your view on the likely costs or impact of such a duty on the NHS? Local Authorities?

20. We agree that this is a good idea and would like to repeat our points at para 10 and 11 above. If local authorities and NHS commissioners are to work together for the betterment of individuals and achieve a fit for purpose system then due regard must be given to the need for sufficiency of community support and treatment. Without the availability of such support and treatment, care of individuals will remain disjointed and fragmented. We believe that such a duty should be a part and parcel of care provisions and therefore do not believe it will negatively impact the NHS in this regard.

21. We consider the key to ensuring that such a duty is as effective as possible is to ensure proper training and guidance is available nationally which takes into account faith and cultural individualities as well as establishing strong links with community organisations. The Muslim Women's Network Helpline for example provides guidance and counselling to individuals on a range of issues including sex, relationships, pregnancy, sexuality, alcohol, drugs and self-harming. The Helpline provides a non-judgmental faith and culturally sensitive service which caters for the needs of the individual; the Helpline is unique in the sense that call handlers are trained to discuss all issues and with the required understanding from a faith or cultural perspective.

22. Utilising existing resources and support services available will also assist in saving time and reducing costs whilst ensuring that the duties of local authorities and NHS commissioners are as effective as possible.

23. For example, a mother called the Muslim Women's Network Helpline to discuss concerns about her daughter's mental health; her daughter has ADHD and was also suffering from depression which had been diagnosed by a doctor. During an appointment session the GP gave them a helpline number; the mother however spoke very limited English and no one was available to speak to her in her mother tongue and they provided her with a different number to call. The mother felt as if she was passed on and no one was available to assist. MWNUK however were able to provide her with a call handler that could speak her language and was able to discuss matters with her and provide counselling and support.

24. More importantly, it is imperative that community based support and treatment services are properly funded and delivered by individuals fully trained and equipped with the necessary resources. Such ideas are irrelevant if real

commitment is not shown towards its implementation. Ideas should be considered with a long-term vision rather than a short-term life span of three to five years; we believe that the issues with such short term action plans, and in turn with such short term funding cycles, is that it does not allow sufficient time to allow design, implementation and evaluation. Where staff are already working at full capacity, adding duties becomes a burden instead and such situations are not sustainable for either staff or patients. Capable and committed professionals who are a vital aid and resource for individuals leave due to low morale and stress. To ensure any additional duties are performed effectively it is therefore essential that support and resources should also be given to staff in order to be able to deliver what is expected.

25. We would also ask that the means of evaluation be considered; if managers do not have clinical knowledge or experience are they truly in the best position to consider effectiveness? It is vital that all personnel involved in the provision of care and treatment hold the requisite knowledge to be able to properly assess the needs of the individual and the effectiveness of treatment and care; otherwise a disservice will occur to both the individuals in need of care and the staff tasked with providing care.

26. Utilising existing resources and support services available will also assist in saving time and reducing costs whilst ensuring that the duties of local authorities and NHS commissioners are as effective as possible.

27. In any event, we would suggest that the benefits of such a duty on the NHS or local authorities would greatly outweigh its costs and would indeed save costs in the future; as more individuals are empowered and given the correct assistance to live their lives as independently as possible and as part of the community this would in turn reduce the burdens on the NHS and local authorities. We are concerned however that due to short funding cycles and evaluation timescales the long term benefits of different services and initiatives are not given proper consideration and in turn good projects may be prematurely stopped. We urge the Department of Health to broaden their vision in terms of providing treatment and care and consider the long term benefits. It must be remembered that autism, learning disabilities and mental health issues can all be lifelong matters in an individuals life; why then are we assuming that the “solutions” in terms of providing effective treatment and care can be found in such a short space of time?

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

28. We note the comments of the Consultation at paras 1.23 to 1.28 and believe that the implementation of this proposal would greatly assist in ensuring that treatment and care is tailored to be person-specific and in turn fit for purpose. More specifically, requiring doctors or Approved Mental Health professionals to provide reasons why a person could not be assessed and treated in the community and therefore requires detention would ensure that proper assessment has taken place of all the possible options and avenues and the needs of the individual taken into account. It will also open the space for a more transparent process whereby the individual or family or friends can review the matter and it will be easier to assess whether due consideration has not been given to a particular factor.

29. We agree that the default assumption should be towards treatment at home rather than detention. However, we would suggest that moving the conversation in one direction rather than the other is not the appropriate solution. The danger of doing so may be that an individual is left without the required support when in fact detention may have been more useful; essentially the inverse of situations now where an individual is detained when care in the community may have been more appropriate. Indeed in the case study referred to at para 23 of this Response, the mother called back the Helpline to inform us that her daughter had attempted to commit suicide. She was sent home from hospital the following day and although the mother urged that the daughter be kept under observation in hospital she was informed that medical professionals would arrive to monitor the situation twice a day for a week instead.

30. Rather, it would be more useful to broaden the information required and ask that doctors and Approved Mental Health professionals provide reasons for both scenarios; that is, give reasons why detention is or is not appropriate as well as why treatment at home is or is not appropriate. By formulating discussions in this manner we will be able to maintain open discussions and ensure that care and treatment is specific and useful to the individual.

31. With such open discussions and added transparency it will also empower individuals and aid their independence as well as that of their carers and family members as they will be able to contribute their views in respect of the options available and be a part of the decision making process. We believe that with such collaborative work this will reduce costs, particularly in respect of tribunal appeals.

32. Furthermore, having such information to hand will assist in future assessments that may become necessary.

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?

33. We wholeheartedly agree with this idea. True empowerment and independence can only be achieved through knowledge of your rights. Moreover, an understanding of the law and procedure can in some cases assist an individual to understand the reasons for which such treatment or care is being pursued. It also provides them with a degree of control over the situation which in itself is helpful in aiding their recovery.

34. Indeed we believe that such information should be widely available to all individuals in society rather than only provided when potential issues may arise. Such information is key in empowering all individuals to take ownership of their situation and understand the help and support available to them.

35. We agree that the information available is confusing and a personalized summary of rights will be of great assistance. Our concern however is whether, in trying to provide a summary of rights that are specific to the circumstances of the individual, certain key points may be missed?

36. We would also like to comment that we have read both the original Consultation document and the easy read version of the same and whilst we appreciate the intentions in trying to make this Consultation more accessible, we feel that the second version is much more watered down version of the original and does not necessarily grasp the full extent of the proposals contained. Our concern in turn is that despite the intentions to assist, the result may actually be the opposite.

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 around options and risks.

37. We agree with the proposal as outlined in para 2.12 of the Consultation: "Where people have the capacity to give informed consent, before they can be admitted to an inpatient setting or to a residential care setting, the relevant NHS body or local authority needs to make sure they have got their explicit and accessibly documented approval or consent. It isn't right for it to be up to the person or their family to have to challenge what is happening to them, it is up to the NHS or LA to discuss, involve and seek agreement with the person. Documentation should record not just a tick box on consent but reflect the fact that a proper discussion of genuine options, risks (including the risks of behavior or health or other problems deteriorating in that setting) and possible alternatives have taken place".

38. We believe that such a procedure will aid the empowerment of individuals and also ensure that professionals make proper assessment of the situation and in turn the necessary treatment and care can be provided.

39. However, we would like to question whether such a process is possible in reality; will staff be provided with adequate time and resources to be able to make such assessments and collate the necessary information?

What do you think about the idea of a gateway or approval mechanism for admissions to inpatient settings, in certain circumstances? What would be the essential elements of such an approval mechanism? If there were to be such a mechanism, should it be given statutory force?

40. We believe that an admission gateway process, where it needs to be demonstrated that it is necessary and appropriate for an inpatient admission or other similar living arrangements to be made (before this takes place), would assist in establishing a fit for purpose system which caters for the needs of the individual as it will ensure transparency and accountability.

41. We question however, whether such an admission gateway process may prolong the process and make it unnecessarily lengthy? We do believe a gateway process would be of assistance but ask that the procedure implemented is timely and not unnecessarily bureaucratic.

42. It is essential to be mindful that the gateway process is not one that only pays lip-service to the role at hand; in other words, the submissions put forward as to why inpatient admission is necessary should be carefully analyzed by the expert group. In turn it is vital that proper training and guidance is provided to all personnel involved in terms of evaluating the evidence and making correct assessments.

43. It may also be useful to consider including lay persons from the community and not just family, and indeed perhaps other service users, sufferers or carers who hold personal insight into such matters.

44. Although the introduction of such a gateway process should be sufficient in itself, giving such a mechanism statutory force is likely to assist in ensuring that it is properly followed and proper consideration is given in respect of assessing the needs of the individual. We therefore feel that a statutory provision should be considered in this respect.

What do you think of the idea of strengthening (for example in statutory guidance) people's rights to request a transfer to a less restrictive setting or a setting closer to home or to ask for a discharge? Do you agree that, as far as practicable, such decisions and discussions should involve professionals or staff based in the

community or expert on community based options? How can we strengthen provider and commissioner accountability in their approach to such requests?

45. We agree with the proposals as set out at para 2.14 to 2.20 of the Consultation; a right to seek transfer or discharges will not only empower individuals and aid a move towards their independence as well as taking ownership of their own care and treatment but it will also ensure that professionals regularly review decisions and make changes as necessary for the betterment of the individual.

46. The process in itself however should be regarded as a right which is considered on a case by case basis as it is not always the case that what an individual or their family members require is necessarily the best decision for them. In this regard, it would be useful to ensure that all requests and agreements, or the lack thereof, are properly recorded with reasons provided for the requests and the like. This not only ensures accountability and transparency on the part of the professionals but it also a useful record that can be used in the evaluation of future treatment and care. Indeed, patterns may emerge which can be utilized to effect positive change.

47. Most importantly however, for such ideas to be properly effective it is essential that the necessary investment is in place to be able to meet the requests; for example, beds. It is pointless to allow demands to be made if they in turn cannot be met; indeed it may be that to do so may do more harm than good to the wellbeing of individuals who are given the impression that their views and wishes are important but are then treated contrary to their wishes. It can make them feel disempowered and indeed can contribute to a continued system of institutionalisation.

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

48. We agree with the proposal outlined at para 2.21 to 2.24 of the Consultation. In particular, we agree that “it is essential that individuals and their families/carers or other advocates have a right to be involved in this process and all care planning processes with a named professional and to have information in a format they can access and understand and within a clear time frame”. We believe that to introduce such a process through statutory guidance will be useful in ensuring that the needs of individuals are met without fail.

49. However, any statutory guidance introduced needs to be supplemented with the necessary resources to meet the agenda as set out in the care and discharge plans. It is unfair to both the individual and the organisation if plans are put in place which cannot be followed through due to a lack of personnel, treatment,

support services, finances or any other resources. If the aim is to provide due care and enable individuals to pursue a good quality of life irrespective of their health issues then proper investment needs to be undertaken in ensuring that all mechanisms and support systems are in place to allow this to occur.

50. We would like to reiterate our comments at para 36 of this Response in respect of attempts to provide information that can be "easily" understood; we hope that in the interests of making information more accessible we do not end up having the opposite effect.

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?

51. We believe that a care plan as well as a plan for discharge should be produced as soon as practicable and certainly believe there should be a time limit in this regard. We are surprised that the Consultation suggests that a care plan be produced "within a specified number of weeks"; we would suggest that a care plan should be provided within one week. It must be remembered that whilst a few weeks may not seem long to us, to the individual involved it can regarded as lengthy. This is especially important to consider given the potential impact on their mental health; it is better to inform them of a plan of action sooner rather than later and this will also assist in them becoming more involved and taking ownership of their treatment and care.

52. We similarly believe that a review date should be specified. In this instance however we do not think a rigid timescale should be pursued as a review date may depend on the individual circumstances of the case; that is, it may need to occur sooner rather than later or vice versa. We would suggest however that the approach should be of a maximum date by which a review should take place; for example, a review to take place at any time but not later than four weeks.

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

53. We feel that the main issue in respect of existing policies and guidance relates to a lack of resources and a joined up approach by which to facilitate an individual's discharge and care in the community. It would for example be useful for a member of the community team to visit the individual as soon as practicable to plan a mutually beneficial discharge but this does not always take place. It is for reasons such as this that we feel statutory guidance will assist in ensuring that appropriate plans are in place to ensure the needs of the individual are met.

The Mental Health Act Code of Practice has just been updated. In line with this, we want to explore how people and their families can be more involved. One idea is

that people and their families or advocates should be able to challenge whether an Approved Mental Health Professional has properly taken into account their wishes and feelings in the interview which takes place before they make an application for admission under the Mental Health Act. What do you think about this idea?

54. We think implementation of this idea will be useful in not only providing individuals with greater control but will also raise the standards of professionals as they will be required to give proper consideration to the individual circumstances and needs of the person.

55. In this regard however, we reiterate the need for proper training and guidance of diverse matters such as faith and ethnicity for all professionals involved irrespective of whether the format of such a proposal is a tribunal or an independent expert or referral to a panel. It should not be assumed that family members are right unless proven otherwise; rather due consideration needs to be given to all key factors involved before coming to a decision.

Which of these options (within the Consultation), if any, do you think would have the most impact? Do you have any views on risks or costs presented by any of these options?

56. We agree that the process for the renewal of a detention needs to be as robust as the original detention decision. Indeed we would consider such a decision to be of even more paramount importance as continued detention instead of discharge may in fact lead to the worsening of an individual's situation; they may feel disempowered, disabled and feel despair. It is important to remember that the proposals contained within the Consultation are to impact on the lives of real people with real emotions. Even if original detention was necessary, it does not mean that it is still necessary or useful to do so weeks or months down the line. It is imperative that the situation is properly assessed, rather than to "lose the individual to the system".

57. We feel that there is merit in all three options proposed; option three in particular is useful as such an approach takes into account wider factors such as community knowledge and experience rather than merely requiring that they are employed within the person's home locality. The key point however is to ensure that the process introduced pursues a similar process of providing real justifications for the continued need for detention and why alternative options, such as treatment at home, is not possible.

58. By ensuring that the needs of the individual are kept at the heart of the decision making process we will be aiding the social inclusion of individuals as well as their independence. We believe that to do so will save costs in the long term and in any event, the needs of the individual and bettering their lives should be considered as the paramount concern.

59. It is important however that any of the options pursued do not become a mere formality and a robust process is put in place which ensures transparency and accountability.

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

60. We feel Community Treatment Orders are a positive mechanism by which to aid an individual's inclusion in the community whilst ensuring continued monitoring of their situation and ensuring that treatment is being followed. We agree however that the decision making process with regard to Community Treatment Orders is less robust than the original detention decisions and feel more can be done in terms of ensuring that the impact on, and needs of, the individual are properly considered before pursuing an order.

61. We would also like to reiterate that we feel that even in regards to Community Treatment Orders much of the effectiveness is dependent on the availability of funding and resources in order to ensure supervision and care. It must be remembered that the individuals under discussion are those with conditions that impact their every day lives. For example, an individual diagnosed with bi-polar disorder may be fine to attend an appointment one day in the morning but not feel able to another morning because they have had a "bad night"; services should therefore take into account the needs of the individual as well as assist the individual to take ownership. They should feel able to call up and say they do not feel able to attend this morning and allow them to volunteer alternative solutions such as coming in the next day after aiming for a good nights sleep or coming in later in the afternoon. However, to achieve such a vision it is imperative that the resources are available to meet the needs. Indeed, rigidity in services can do more harm than good; if a person with bi-polar disorder is told that they have to attend at a particular time and not being able to do so is considered a breach irrespective of the reasons behind it then naturally a person will feel disempowered and would also be unlikely to be honest about their circumstances.

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 of this idea?

62. We are in agreement with this idea; the lived experiences of individuals should form the basis of all decision making processes and in turn organisations who adhere to this view should receive contracts to provide services. Indeed, it is surprising to note that self-advocates and family advocates are not automatically involved as such in some organisations given the wealth of experiences that are available through them.

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

63. We welcome this suggestion and believe that this will act as a further means of support and will aid individuals to empower themselves. However, the availability of IMHAs should not be regarded as a substitute for essential legal support or indeed as sufficient in terms of informing an individual of their rights. The availability of an IMHA should be an additional resource and not a replacement.

64. We would propose that all IMHAs are provided with proper training and guidance to ensure that they are able to properly take into account faith and cultural factors that may be involved.

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

65. We are unable to provide comment in this respect. Patient confidentiality is a serious matter and we do not think it should ever be assumed that all safeguards are in place and nothing further needs to be done to protect a patient. Rather we feel that the approach should be of continuously reviewing the safety mechanisms in place and doing so for each individual case; after all, circumstances can differ very much between cases and it is vital to always remain alert.

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

66. We do appreciate the points raised at para 2.50 to 2.55 of the Consultation and do consider it necessary to review the laws in respect of determining the nearest relative. We also agree that an individual should be given more autonomy over who they consider to be their nearest relative, and would reduce the cost of displacement and disputes.

67. We would however like to highlight a particular issue that was uncovered through our report 'Unheard Voices'. A 30 year old woman with learning disabilities was being sexually exploited by men and moved across three different regions. The police stated they were unable to do anything because the victim had informed them she was complying through her own free will. This was despite the fact that her learning disabilities were clearly evident. We highlight this case as an example of situations where an individual's choice of their nearest relative or nearest kin may appear to be a sound and autonomous decision but in reality they may be at further harm from the said individual.

68. On a similar note, BME individuals with mental health issues and learning disabilities may be at risk of a forced marriage; their family members may in turn not be the best persons to be informed of their circumstances or given control of their treatment.

69. We also have a recent case study whereby a daughter who was caring for her elderly parent returned home one day to find that her mother was missing and it transpired that the mother had been moved by her sibling (whilst she was out) nearer to them so that they could act as carers instead. It is therefore imperative to remember that not all family members will hold the best intentions for their kin. We do wonder whether in some cases, assumptions of a caring culture arising out of duty within Asian and other BME communities are perhaps at play as a result of which the intentions of family members are assumed to be in the best interests of the individual? It may be useful to consider research in this regard and certainly include such discussions within training to ensure that professionals are equipped with the necessary knowledge to be able to make a proper assessment of the needs of the individual.

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?

70. We agree with this proposal provided that proper resources and funding are made available to support the implementation and effectiveness of such added responsibilities. We do not see any merit in adding to the burdens of social workers if at the same time measures are not taken to ensure that they are in fact able to fulfil the expectations.

71. We are also aware of social workers who have been unable to notice signs of other factors at play in BME sufferers, such as sexual exploitation, and in turn would suggest that training and guidance is rolled out on a national basis in respect of issues such as sexual exploitation, forced marriage and FGM. If the aim is to promote community based plans and attend to the needs of the individual then it is vital that all issues involved are properly assessed. Indeed mental health matters can be linked to various forms of abuse; it should not be assumed that one can be addressed without the other.

72. This once again leads to the discussion in respect of the adequacy of funding and resources available. Are social workers provided with the necessary training, guidance and most importantly time, to consider the needs of the individual and forge trusting relationships on a professional basis with individuals and their families? As it currently stands, we believe the answer is no and without true dedication to empowering professionals such as doctors and social workers to be

able to carry out their work it is pointless to assume that any proposals within the Consultation will have any lasting effect.

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

73. The main need is to provide an outlet by which people and families are able to raise issues, and in fact they should be provided with such an outlet even if something has not yet gone wrong. Medical professionals should have open discussions about care plans and treatments and allow room for debate and discussions in respect of these. The culture should be to work together to aid the individual from the outset; such an approach should in turn reduce the need for complaints.

74. Information also needs to be more readily available and be both comprehensive and easy to understand. Indeed we feel that steps should be taken to promote awareness of rights and responsibilities on a larger scale to the wider public more generally; this we feel would be especially useful for those within Muslim and BME communities as it will aid in increasing awareness and understanding of mental health matters and learning disabilities as well as empowering individuals with knowledge in respect of their rights.

Which options 1), 2) or 3), if any, seems most appropriate? What is your view on the potential benefits or unintended consequences of the options set out?

75. We do not currently feel able to comment on the appropriateness of the three options without having sight of any exact proposals to change the law in this respect.

76. In the first instance however, we feel there is merit in option 2 and option 3 and look forward to receiving further information and hope to be able to provide further comment in this regard in the future. We do feel it is unfair and inappropriate that individuals with learning disabilities and autism fall within the remit of the Mental Health Act and detained for treatment purely because their behaviour arising out of their conditions is deemed as challenging or "odd".

77. We note that it appears from the discussion in respect of option 1 and 3 that a key reason against excluding learning disabilities and autism from the Mental Health Act is because this would mean that courts would therefore be unable to divert offenders, or those accused of an offence, to an inpatient setting. This highlights a key failing in the police and courts processes whereby the individualities and needs of those with autism and learning difficulties and in turn these failings need to be addressed rather than to punish those with autism and learning difficulties by keeping them within the remit of laws that are not fit for purpose in respect of their needs.

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?

78. We think this is a good idea and will assist in simplifying procedures for both the individual and the organisation.

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?

79. We believe a clarification in law in this respect will be useful and will aid all individuals, their carers and families, professionals and organisations to work collectively in unison to achieve a fit for purpose system and assist in achieving a better quality of life for individuals.

What is your view on the proposal that children and young people ages under 18 detained under sections 135 or 136 should never be taken to police cells? 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? What is your view on any other recommendations in the Review?

80. We are wholeheartedly in agreement with these suggestions and indeed would suggest that the proposal needs to be taken a step further and police cells should not be used for any individual in mental health crisis. If an individual broke their leg, would we in turn send them to a prison cell for the night?

81. The use of police cells adds to the stigma and negativity surrounding mental health matters and is especially the case in respect of Muslim and BME communities whereby an individual would be dually ostracized; first for having mental health issues and secondly for being deemed criminal. For some in BME communities, the mere fact that there was police involvement in your life is sufficient to brand an individual as a criminal irrespective of the reasons in this regard.

82. More importantly, we are aware of systematic failures by the police when dealing with individuals with mental health issues, learning disabilities and autism which in turn highlight that the police are not equipped to deal with individuals suffering from such conditions.

83. Muslim and BME women are in particularly danger of having their mental health difficulties being used against them. In one example, a victim of domestic abuse was threatened with arrest by police officers for being hysterical and the fact that being beaten by her brother in law may have caused such behaviour was not considered; in fact it appeared the police officers had a level of sympathy for the perpetrator, helped by the fact he was able to speak to them in

fluent English whilst her distressed state and language barriers made her come across as incoherent – and therefore to blame. In fact, it appears that suggesting a woman has mental health issues appears to be an easy way to defend oneself and place the blame on the victim; for example, where a woman made a complaint against her employers, she was accused as such and the police threatened to arrest and charge her for harassment instead.

84. We would also like to highlight the particularly vulnerabilities of Muslim and BME individuals who suffer from the likes of bipolar disorder, schizophrenia, autism or Asperger's syndrome. We are sure that concerns will be raised for police to exercise caution with regard to all such sufferers, but we are concerned that stereotypical notions of Muslim and BME individuals, including of being terrorists and extremists as well as other racial stereotypes, has lead to both physical and emotional mistreatment of sufferers. We refer to the recent case of Faruk Ali for example, a man with severe autism who was beaten in the street by two Bedfordshire police officers because he allegedly "looked suspicious".[4] We must also highlight the fear of members of such communities when they hear of the case of Talha Ahsan, a Muslim and BME man with Asperger's Syndrome who was extradited to USA, when compared to Gary McKinnon whose extradition was halted due to suffering from the very same mental health diagnosis[5]. We hope it is appreciated that this only assists in further isolating sufferers within the Muslim and BME communities, with family members restricting movements outside the home in a bid to protect them from police themselves. Moreover, the stigma and generally dismissive attitudes prevalent within such communities can mean that many conditions go undiagnosed and it is vital that police are aware of this aspect for they may be the first opportunity presented for the individual to receive a diagnosis and in turn, professional help.

What is your view on the review proposed 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?

85. We think this is an interesting proposal and think it may be useful to introduce such a power for the likes of a social worker or care coordinator; we look forward to hearing further in this regard. We reiterate once again that any such proposals will not be effective without proper training on faith and cultural factors that may be at play.

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

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[4] http://www.bbc.co.uk/news/ukDenglandDbedsDbucksDhertsD26443846

[5] http://www.huffingtonpost.co.uk/alexDmacdonald/garyDmckinnonDtalhaDahsanDaspergersDsyndrome_b_1969748.html

86. As we have attempted to highlight throughout the course of this Response we feel the key practical considerations to take into account are that of ensuring proper funding and resources are dedicated to developmental work and the implementation of the various proposals. It is irrelevant to put forward ideas if the necessary commitment will not be shown into turning these ideas into actions.

87. It is also imperative that the diversity of individuals is taken into account if a truly fit for purpose system is to be achieved. Thus, due consideration needs to be given to faith and cultural factors that may be at play and specific individualities need to be taken into account.

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 their liberty? 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?

88. We note that in some cases for various reasons some patients will need very intensive and potentially restrictive conditions placed on them in respect of discharge in order to allow them to live in the community in a way that ensures their own and others' safely. We also note that the Mental Health Act only provides for detention in a hospital when deprivation of liberty is an issue and therefore an individual cannot be discharged from detention in a secure hospital into a care home if they become subject to conditions that amount to a deprivation of liberty.

89. We fill this is at odds with the aims of ensuring that treatment and care is centred around an individuals' wellbeing. We agree with the comments at para 3.28 of the Consultation that this is not compatible with guiding principles that "the right care is care in the least restrictive setting possible. It also adversely affects a number of people with learning disability or autism spectrum conditions who have behaviour that may challenge, or those with mental health problems who are currently in inpatient settings and who could, or should, be moved to alternative less restrictive settings – even where such a setting would still amount to a deprivation of liberty". We are concerned that in some cases individuals will not be provided with the correct care and support due to technicalities in the law. We are therefore, in principle, in agreement with the suggestion that the Mental Health Act be amended 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 their liberty.

90. Implementation of such a procedure however will need to be transparent and robust in order to ensure that a discharge with conditions for restricted patients is given the required level of consideration with proper analysis of the evidence available. We look forward to hearing further from the Department of Health in respect of this proposal.

91. We do think it would be useful to consider other forms 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 into a community based setting. We feel that this would assist not only in promoting the individual's wellbeing but also assist the organisation by relieving the burdens on the hospital; that is, they will be able to concentrate on and provide appropriate care to those that require detention in hospital. Meanwhile an alternative form of detention, with trained professionals capable of managing treatment and care in this form, will be able to meet the needs of those that do not need to stay in hospital. This would aid the development of a system that is fit for purpose whilst also allowing adequate monitoring for the safety of the patient and others.

Which of the options above (option 1 or option 2) do you think would be most effective? What else might need to happen in order for such Personal Health Budgets to enable people to choose new providers and/or new kinds of service or interventions? How can we ensure that the new arrangements under the Children and Families Act can also be used to prevent unnecessary admissions in adulthood?

92. We believe there is merit in considering both options, but at present would consider option 2 to be potentially more effective in that individuals who are subject to the Care Programme Approach will have more of a plan in place by which to utilize the availability of a personal health budget. We also feel that option 2 is wider in its reach, although we are concerned that some may fall outside of the criteria of both options and would be unable to utilize the opportunities.

93. The key consideration is the level of support and resources available to enable individuals to manage their personal health budget as effectively as possible so as to live as independently as possible. It is unfair to base successes or failures of providing personal budgets if in actuality there is not much choice available as to how it can be used. If the required level of support and resources are not provided, the likelihood is that unnecessary admissions in adulthood would continue.

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

94. We note the comments at 4.19 to 4.26 of the Consultation and believe specific pooled funding may be useful, especially as it will form as a further means by which different stakeholder organisations will be made to work and think collectively as to how best to serve the needs of the individual so as to promote their wellbeing and inclusion in the community.

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

95. We would like to reiterate our comments at para 86 and 87 of this Response; local accountability is strengthened when the necessary commitment can be demonstrated in wanting to achieve a system that is fit for purpose and truly places an individual's wellbeing at the heart of the decision making process. To achieve this it is imperative that proper funding and resources are dedicated to fully implementing services and involving individuals and their families.

96. We also think it would be useful to forge connections with community organisations who can act as an additional means of support for individuals and provide insight into key issues.

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?

97. In order to properly assist an individual it is important that all professionals involved are able to work together in unison and are able to properly assess the needs of the individual. Naturally all the necessary information in respect of the individual or patient is required to be able to make a proper assessment. In turn we feel that there should be a duty to share patient information with case managers and other relevant commissioners directly involved in arranging a person's care in certain circumstances.

98. We do however stress that this such an information sharing exercise should only take place where deemed necessary for the wellbeing of the individual and only to those directly involved in arranging treatment or care. Confidentiality is a serious matter, especially in regards to such personal and intrusive information; where possible the individual's consent should be obtained. Where information has been shared to others this should be recorded in order to maintain transparency and accountability.

What are your views on how we could be clearer around responsibilities of: clinical commissioning groups, providers, medical directors, and responsible clinicians; for the physical healthcare of people in mental health inpatient settings?

99. Physical health is far too often not addressed nor managed adequately for patients with mental health issues and/or learning disabilities. The fact that physical health outcomes for such individuals are far worse than the general population is in our opinion scandalous and it is vital that this is addressed as a matter of priority.

100. Doctors may for example, focus on the mental health diagnosis and forget about other key issues of consideration such as the weight of the individual or smoking habits even though addressing these issues would have a huge benefit not only from a physical health perspective but also in terms of mental health matters; indeed such considerations may form a part of a bigger picture which explains the individual's mental health situation which are unfortunately not being looked into due to time constraints or a lack of other resources.

101. Where time is spent addressing a patient's weight or smoking or drinking habits it may have a positive effect in the sense that the individual will see that they are being regarded as a person as a whole rather than just a mental health patient. By providing the due care and attention it may indeed bolster an individual's own feelings of self-worth and allow them to take steps forward to address their situation.

102. We believe there needs to be clearer guidance in respect of who is responsible for the physical healthcare of these patients and furthermore a requirement to address physical health may prompt clinicians to carry out proper assessment of the circumstances of an individual case rather than overlook such matters and this could be through local and/or national avenues.

103. In turn we do believe that there should be more clarity in terms of the responsibilities of clinical commissioning groups, providers, medical directors and responsible clinicians for the physical healthcare of people in mental health inpatient settings. Although various methods can be used to raise awareness of such and achieve clarity, such as literature or workshops, we feel the simplest format would be clarify the responsibilities in conversation with the individuals themselves.

Thinking about all the things described in the document: which would have the greatest impact and benefit on people's lives? Which carry the greatest potential costs or risk?

104. We do feel that a number of useful and positive ideas have been put forward within the Consultation and commend the Department of Health for placing an individual's wellbeing at the heart of the discussion. In turn we

believe the greatest impact and benefit to people's lives will be achieved by ensuring that the individual is placed at the heart of all care planning and decisions and their best interests and wellbeing given utmost priority.

105. We also feel it is imperative that all key stakeholder organisations work collectively and in unison, with the same aims and objectives in mind when considering the treatment and care of the individual. Multi-agency working with adequate information sharing facilities (with the necessary safeguards in place to protect the patient from unnecessary breach of confidentiality) and proper training and guidance to take account of individual, faith and culture factors would greatly assist in achieving a system that is fit for purpose and truly takes the needs of the individual into account. However such an impact can only be achieved with proper commitment in the form of funding and resources which would ensure that the required treatment and services are available and most importantly would assist in the social inclusion of individuals in the community and allow them to live a good quality of life.

Final Comments

106. As a point of clarification, we must explain that our comments and examples have been limited to BME and/or Muslim victims due to the nature of our organisation and its work. As a national Muslim women's organisation our work predominantly deals with Muslim and BME women albeit we also work with individuals of other ethnicities and faiths and are therefore also aware of issues of relevance to other communities. In turn we wish to clarify that where we ask for faith and culturally sensitive support packages and mechanisms we do so on behalf of victims of all race, ethnicity, religion and faith.

107. As a national women's organisation committed to changing attitudes to mental health and other health issues, Muslim Women's Network UK would like to express its willingness to assist through training, support, information or advice or any other means that will promote equality, diversity and social inclusions of all individuals.

108. We would like to thank the Department of Health for providing us with the opportunity to respond to your Consultation and hope that our Response proves to be helpful in your considerations.

On behalf of Muslim Women's Network UK,
Nazmin Akthar-Sheikh
Vice-Chair

Muslim Women's Network UK
The Warehouse

54-57 Allison Street
Digbeth
Birmingham
B5 5TH