Family Carer Support Service response to:
No voice unheard, no right ignored: a consultation for people with learning disabilities, autism and mental health conditions

Hft’s Family Carer Support Service (FCSS) provides information and support to family carers of people with a learning disability anywhere in England.

We do this by responding to individuals who request help by telephone, email and letters; through participative workshop courses so groups of relatives acquire skills and knowledge they need to understand and engage effectively in processes affecting their relative and themselves; the production of resources specifically tailored to the support roles family carers play throughout phases and aspects of their relative’s life; and by working in partnership with others to help raise the profile of family carers, their needs and contributions, in research, health and social care, as well as mainstream initiatives.

Introduction

This Family Carer Support Service response to the consultation ‘No voice unheard, no right ignored’ includes the views of family carers supporting relatives with learning disabilities.

The consultation green paper was published in March 2015 by the Minister of State for Community and Social Care who was in post at the time, Norman Lamb. The consultation reflects the Minister’s aim to strengthen the rights of people with learning disabilities and their families, allowing greater control and choice on how care and support is received.

Alistair Burt has recently replaced Norman Lamb as the Minister of State for Community and Social Care. We urge Alistair Burt to continue to build on Norman Lamb’s work and develop policy that will improve the lives of thousands of people with learning disabilities, autism and mental health and their families. Alistair Burt has said on Twitter that he follows a “decent and hardworking compassionate colleague”, and is keen to “listen to him and build upon his work” so we hope this translates into action.

Burt is also the president of Carers in Bedfordshire and his website states that he “has been active in issues regarding carers” which we think is promising as he should be familiar and committed to supporting family carers to overcome the very important issues outlined in this document.

The Disabled People (Community Inclusion) Bill 2015, also known as ‘LB Bill’ is a private members’ bill, produced and developed by family carers, people with learning disabilities and professionals. We think the proposals in the LB Bill are well considered and would work to truly improved the lives of people with disabilities. We urge the current Government to consider adopting the Disabled People (Community Inclusion) Bill 2015. https://lbbill.wordpress.com/

The Family Carer Support Service response to the consultation is below.

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May 2015
Q1 The Care Act says that local authorities have to put individuals’ wellbeing at the heart of what they do. We want to explore whether NHS commissioners should have the same duties, for example, for people with learning disability or autism who are at high risk of long stays in hospital in relation to their lifelong needs. What do you think of this idea?

We welcome the proposal for NHS Commissioners to have the same duties as Local Authorities in relation to the lifelong needs of individuals with learning disability and/or autism. It makes perfect sense for health and social care providers to have equal regard to individuals and their family carers.

The duty should also be extended to having the same duties in relation to lifelong family carers supporting those individuals. The duties should be extended to all NHS staff, not just Commissioners.

Family carer: “The Care Act is of utmost importance and the duties of wellbeing for all people working in health and care. A discharge plan MUST be in place as soon as possible after admittance. A planned programme for their treatment must be put in place and also visiting arrangements for family and maybe friends and how they are able to keep being part of the community”.

Q2 In determining living arrangements – (whether suitable accommodation or inpatient stays) – both LAs and NHS commissioner could have to have regard for factors which support inclusion in the community, staying close to home, links with family and friends and opportunities for participation and the least restrictive setting? What do you think of this idea?

Options for support provided in the community must always be considered before inpatient admissions. This should be the default position with LAs and NHS having to provide strong evidence to propose an inpatient stay.

Family carer: “Yes, it is important to have the person you love and care for close to home if possible, my daughter would be only if her needs are fully met”.

Q3 What might the appropriate length of inpatient stay be where this should apply for the NHS?

The length of any inpatient stay must be based on a person’s needs, situation and wishes; the appropriate time spent as an inpatient will differ from person to person, depending on these factors.

Any individual admitted into hospital should have a discharge plan from the first day of admission, with set review dates and other important milestones and/or meetings. There must be a named responsible person to keep the person and relevant family members up to date and to answer questions they might have.

Family carer: “Joint commissioning and joint working is a MUST. If the discharge planning is in place then there should be regular meetings to avoid extending a stay in hospital longer than necessary”.

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

If budgets are combined and the money follows the individual, there should be little impact, other than streamlining their work. Clear guidelines about how funding disputes are managed would help LAs, CCGs, individuals and family carers.

**Family carer:** “There will be more work in ensuring it happens to start with, but in total less work if the placement is correct first time”.

**Family carer:** “The main factor will be cost. Who pays? More often than not this is very costly on the local authority and the CCGs. Should not NHS England (Government) be responsible for some of the funding?”

Q5 We think that local authorities and clinical commissioning groups could have to think about how to ensure there is 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?

In order to carry out proposals in Q2, this is an essential element of the commissioning role. Local Authorities and CCGs must work collaboratively to achieve a thriving market place with highly skilled and well trained staff.

**Family carer:** “It is essential that this happens and happens soon. We need local provision in the community available”.

**Family carer:** “I agree but there must be care taken that where they are living in the community is safe for them and for the “community”. Proper risk assessments should be done and updated when it is necessary”.

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

Individuals and family carers find health and social care systems difficult to understand and to navigate, often due to lack of communication and/or inconsistent messages. A named person for each area would improve accountability and better communication.

**Family carer:** “To make it effective, make it legally binding and have recourse to the law”.

**Family carer:** “Fines”.

**Family carer:** “Plan plan plan, listen listen listen. I have been saying for 15 years that this is needed but it falls on deaf ears. If you plan when the child is early teens it may be there by the time it is needed”.

**Family carer:** “Ensure that family voices are heard, especially if they feel that their family member needs more support”.

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Q7 What is your view on the likely cost and impact on the NHS or local authorities?

Family carer: “If done properly it should prove cost effective. It will negate crisis cheque book mentality, ie place them here they have a space. It may be more expensive to start with, but will save money in the long run. Community provision close to family friends and professionals that know them means they can be visited often and ensure their wellbeing is OK”.

Family carer: “How will the local authorities and the NHS be able to keep funding all those other people who needs funding. Is the Government going to give extra funding to the Local Authorities to cover the cost of implementing the Care Act funding reforms?”.

Q8 What do you think about the idea to change the information required by Mental Health Act regulations in the application 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.

We agree with this idea; it is incredibly important to demonstrate how options have been considered by professionals. Even if the outcome is not agreed by the individual and/or family, a better understanding of how the decision has been reached will improve communications and ultimately result in better outcomes for the individual. We know that many people are receiving treatment in Assessment and Treatment Centres that would be better supported in the community if the right support is provided with highly skilled and well trained staff.

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

This is essential, however care needs to be taken over the named professional’s level of knowledge and experience of working with individuals with LD, Autism and mental health and their families. The Learning Disability Liaison Nurse may be in the best position to hold this role; however we know they are not present and/or available in all areas.

Information must be provided in a way that works for the individual and the family carer. This might be in easy read, but it also might be braille, audio tape or other communication methods such as the use of talking mats etc.

Family carer: “It is essential that those supporting the person and the person themselves have information that is easy to read and understand”.

Although the family caring role is lifelong, by the time their relative reaches adulthood, they still need to be kept informed and involved with the constantly changing health and social care systems.

Family carer: “It is vital that every carer has a named professional to help, support and advise or signpost them. We carers spend many hours trying to find out what next step we should take. When our son was born, we needed weekly meetings; age 2, monthly meetings; age 5-18, four monthly meetings; 18 onwards, annual meetings. It is appreciated that it sounds like a lot of
professional hours, but I suspect that we used three times that number explaining our son’s situation over and over again to yet another professional. We, and those we care for are not numbers to be found on a computer; we are people who need help and personal communication. In the long run it will save central and local government and the NHS money”.

Family carer: “Yes of course. Has a ‘Best Interests’ meeting been held and are the person and their family kept up to date about treatment and discharge. Also are plans made with the person about their short and long term future accommodation (and support). The individual and their family should be offered information and an advocate each”.

Q11 What do you think about the idea that local authorities and NHS bodies 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.

We welcome this proposal which is in line with the principles of the Mental Capacity Act. It is best practice to make every attempt to communicate with someone in the best way for them to support their understanding. Documenting conversations and decisions, particularly around consent, must always take place.

Statutory Guidance should clarify what should be expected from this process.

Family carer: “A good idea and could be a best interests meeting for those lacking capacity”.

Q12 What are your views on the idea of a gateway or approval mechanism for admissions to inpatient settings, in certain circumstances?

We think this is an excellent idea and should apply in all circumstances. The proposed approval mechanism will safeguard against people being inappropriately detained in hospitals.

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

A right to challenge would be fundamental.

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

Yes, absolutely. We know that where statutory force is not in place, guidance is often not adhered to.

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

Individuals and families must have the right to change their mind and we are pleased to see the proposal is that ‘any requested transfer should happen as soon as practically possible, unless there were clear reasons why not’. We have seen legal ‘rights to request’ in the past, for example with Carers Assessments that are requested but not provided.

Family carer: “It is essential that this is available”.

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

We agree.

Discussions about options for community support for an individual who is an inpatient must involve staff who have expert knowledge and current experience of community support available. They will be able to inform the individual and their family of what is available and explain how certain types of support have helped others. Experts on local community support would be able to discuss managed risk taking with a stronger knowledge of what is available. A joint approach is essential to ensure a streamlined transition from hospital to home.

Family carer: “Yes but I worry about confidentiality”

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

If this were linked into a Statutory Gateway or Approval Mechanism, it should provide suitable safeguards. A right to challenge would also be essential.

Family carer: “Have approved provider lists that are agreed with carers and service user reps. Do not use a provider just because they have a space. There may be a good reason for spaces”.

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

We agree. We know from experience that non-statutory guidance is often not followed and this can be difficult to challenge.

Family carer: “Yes I believe discharge should be planned on admission and planned with the funding authority and family as well”.

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

We welcome a duty for care plans and discharge plans to be produced at the earliest opportunity with the individual and their family carer. Meetings must be timely and reviewed appropriately – we know that ‘reviews’ have taken place with little input or real thought about the individual’s situation. Reviews must not simply be a ‘box ticking’ exercise.

Consideration must be taken about who attends meetings and advocacy support must be available for family carers. We know many family carers have attended meetings alongside 10+
professionals with no formal support. Family carers and individuals can find this incredibly intimidating and difficult to engage with. Meetings must be accessible in all ways.

**Family carer:** “Definitely. This should happen and happen very quickly, 1 week should be long enough for good providers to have paperwork complete, if not 2 is the maximum. For some this could be life or death. it is essential to include those who know them best; carers and support workers”.

**Family carer:** “Every person with a learning or physical disability needs a care plan.

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

Individuals and families should be able to challenge professional practice at any stage, particularly early on in the process. Where an AMHP has not properly taken wishes and feelings into account, a challenge would be essential to divert potential further crises and/or unnecessary dependency on services.

Q22 Which of these measures, [3 potential options for safeguards around renewal] if any, do you think would have the most impact?

We agree that renewals and decisions not to discharge should be strengthened to be as robust and have the same safeguards as the original admission. Option 3 would have the most effective impact on this; a professional with strong community knowledge and experience would be in a good position to highlight alternative options to detention.

We welcome that individuals, family carers and/or advocates may be able to nominate potential professionals to carry out this role and we would be keen to be involved in discussions about how this might work.

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

**Family carer:** “As with all things may not save money initially but will in long run, need not only to think of costs, need to think of benefits to person”.

Q25 Guidance could say that only organisations that include self and family advocates in their governance should get contracts with the local authority or the NHS to provide services for people with learning disability or autism. What do you think about this idea?

We welcome this idea in principle, however there would need to be very clear criteria about what is seen as governance in this context. Would a self-advocacy group, made up of people supported by the organisation and feeding their views to Trustees or the CEO be regarded as governance?
Or would the requirement be to have at least one Trustee who represents the group of people the organisation supports?

Any involvement would need to have purpose and be meaningful with real outcomes. We wonder how this could this be monitored by the Department of Health? We know that many people with learning disabilities and other disabilities are ‘involved’ in governance of organisations in a tokenistic way that has little value to the organisation or the individual.

**Family carer:** “Not sure about this there are good providers that do not have this and should not be rejected just because of this. However that said it is a good idea to get all providers to think”.

**Family carer:** “In my experience, self-advocates can and do make a significant contribution, but I don’t see how it could be made compulsory. A family advocate would almost certainly be helpful; how many have the time from their work and caring roles?”.

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

We agree with the proposal for IMHAs to be available to patients who lack capacity on an opt out basis. Presuming the Mental Capacity Act is correctly followed, this would be to the benefit of the majority of patients.

**Family carer:** “IMHAs should not only be available to those who lack capacity but also those in the grey area, certainly for all those who have no family or friends who can support them. Capacity is determined for one decision. Confidentiality – one does not expect information which is of a private nature, but if they are returning to the family home, or a staffed residential home, surely the parent or the staff must be informed about medication and what to expect. This is safeguarding both the patient and other people they live with”.

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

There are laws in place to safeguard around information sharing. If the Mental Capacity Act and Data Protection Act are correctly followed, information should be appropriately shared in certain circumstances.

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

We welcome this proposal. There are many instances where the ‘nearest relative’ is not actually the person who knows the individual best, causing difficult situations and further deterioration of psychological wellbeing. A nearest relative who does not know the individual well is not in a position to appropriately engage in MHA processes.

Giving individuals the option to choose their ‘nearest relative’ would require good guidance about the role of the nearest relative – provided in accessible formats to support understanding for people with different communication methods.
Family carer: “This could be very good idea, but it must be seen in the fact that some people are easily swayed and may choose the wrong person. A best interest meeting style meeting could help”.

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

Yes. This would result in smoother process for many individuals and therefore fewer disputes.

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

The role of the family carer is lifelong. By the time their relative is an adult, they have usually had a multitude of professionals come and go in their lives.

Family carer: “This is the most important question. Not only will it save money, it will save marriages and lives”.

There is a great deal of evidence to show that individuals and family carers have better experience of health and social care processes when they have a key contact to keep them involved and informed. Continuity and consistency of communication is also fundamental.

A named professional would be welcomed, however a social worker may not be the most appropriate person. It is uncommon for an individual to have an allocated social worker in the current health and social care landscape and the nature and quantity of their work does not allow for the development of strong relationships with the person and their family carer. A named professional must be one who knows the individual well, is a well-established post and can communicate effectively with family carers.

We would welcome a proposal for the individual and family to be involved in deciding who would be that named professional.

Family carer: “Yes, but have the choice to elect an alternative responsible person other than a social worker”.

Family carer: “Sounds very good BUT the social worker etc. must have power to decide. It should not then be overruled at panel. I.e. if a decision to have community facilities is the best for the person, but panel decides it is too expensive the decision on the persons needs should have power to challenge panel.”.

Family carer: “Where are you going to find enough social workers? This is a good idea, but who chooses their social worker? If it is found that they are not doing a good job, who do the clients go to, to make a change?”.
Q32 Which of options 1) 2) and 3), if any, seems most appropriate?

Option 3 is the most appropriate. Learning disability and autism are not mental health conditions and must not be regarded as such. We agree that there is a need for diversion from the courts so excluding people with learning disabilities or autism from the civil and not the criminal justice sections makes sense.

Is there an option for people with learning disabilities or autism to be diverted from the criminal justice system with other legislation?

**Family carer:** "In my opinion, mental disorder should not be used to describe a person with a learning disability or autism. Surely if being admitted to hospital or treatment, the wording should be for example “A has a learning disability and is suffering from…”

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

This sounds like a good idea in principle. We welcome a proposal to improve and streamline detention criteria.

The consultation document comments that ‘it can be hard for patients and their families to understand these complex different rights’ (3.11). We would argue that it is also difficult at times for professionals and so therefore communications about roles, rights, responsibilities and processes are not as clear as they could be.

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

We agree with this idea.

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

We absolutely agree with this proposal.

Q37 What is your view on the proposal that the use of police cells for those over 18 should be limited more in terms of frequency and length of detention as proposed by the review?

We agree in principle, however the use of police cells must be an absolute last resort as described in the consultation: ‘significantly reduce the use of police custody as a place of safety for adults so that it becomes a **genuinely exceptional event**’ (3.22).
Q39 What is your view on the review proposal to create powers for professionals other than the police to be able to take a person from a public place to a place of safety?

We agree with this in principle, however, there would need to be very clear Statutory Guidance, ongoing training, monitoring and a requirement to be registered with a professional body such as the Health and Care Professions Council.

Q41 Do you think it would be desirable in principle to amend the MHA to enable restricted patients to be discharged by the Secretary of State for Justice or a Tribunal subject to conditions amounting to a deprivation of their liberty?

Yes, with clear Statutory guidance on how to work with the Mental Health Act and Mental Capacity Act.

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

Yes. Could this be similar to S117?

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

We would like to see all people with learning disabilities or autism who have mental or physical health needs to have a legal right to a PHB. The Confidential Inquiry into premature deaths of people with learning disabilities highlighted many concerns around equal access to health provision. We know that PHBs can have a hugely positive impact on the lives of individuals and their families.

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

Joint planning and pooled funding that follows the individual would allow for more creative ways of budget spending to prevent admissions and to speed up discharge processes. Experience shows that bureaucracy often delays and prevents personalised approaches to supporting individuals which is proven to be most effective.

Family carer: “It would be helpful to stop infighting and budget games between NHS and Social Services”.

Family carer: “Ring-fencing the money would be essential so people with learning disabilities, autism and mental health do not come off Politicians’ ‘radar’. If the money isn’t ring-fenced, it will be hived off to other areas such as dementia”.

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

Family carer: “Community Support should be the priority and the first action taken before anything else.”

Family carer: “Reports to Learning Disability Programme Boards and to Health and Wellbeing Boards but with teeth. I.e. a need to do it and act upon it”.

Family carer: “Individuals, voluntary organisations and solicitors must study the Care Act and lobby the local council to ensure that they comply”.

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

We agree with this idea in principal. Clear statutory guidance would be essential.

Family carer: “I have no experience of mental health, but if it is like other health and social care, it seems to me that more legislation leads to more ticking of boxes and less hands on care”.

Family carer: “Only with the knowledge of the person or their carers and only if it benefits the person”.

Q49 What are your views on how we could be clearer around responsibilities of:
clinical commissioning groups
providers
medical directors; and
responsible clinicians
for the physical healthcare of people in mental health inpatient settings?

Family carer: “As someone whose daughter is out of area, I firmly believe that the placing authority should remain responsible for ensuring that all the persons needs are met. Not for providing them, but ensuring they happen. Providers should ensure they get all needs met. Medical directors MUST ensure all health needs are met and responsible clinicians again should have a role too”.

Family carer: “There should be a holistic approach as a person’s mental and physical health are of equal importance”.

Family carer: “The physical health is of prime importance and it should be the overall responsibility of all the organisations listed, but also those who have the day to day care of the inpatients. Sir Jonathan Michael’s recommendations and the CIPOLD recommendations should be used and followed”.

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Q50 Thinking about all the things described in this document: which would have the greatest impact and benefit on people’s lives (so we know what should be highest priority)?

**Family carer:** “Ensure that LAs and CCGs plan for the needs of the whole population locally. Do not send those with high cost, low incidence needs, out of area. Plan and provide local facilities that fully meet the needs of the whole person”.

Which carry the greatest potential costs and risks?

**Family carer:** “Not planning for the needs of the local population and sending people out of area will cost more in the long term”.

**Family carer:** “The profit motive should be removed and all provision should be not for profit or charitable”.

A family carer highlighted a very important aspect that has not been addressed in this consultation. We think her points are extremely relevant and important and would like them to be noted:

“There seems nowhere to include feedback on the additional **cost** when illness or medical needs arise when supporting someone who needs daily support or care routinely in their normal life. The ramifications are considerable. Extra transport to and from hospital, parking fees, getting someone to help with the consequences of a disrupted routine etc. Much greater care needs, therefore additional costs. It’s not just the healthcare. If social and wellbeing considerations are to be maintained, the same is true. The costs escalate if someone needs much greater support to maintain those links in times of difficulty. And perhaps that is exactly when friendships and social distractions are so important for wellbeing and state of mind”.

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