EASY READ FEEDBACK FORM *Caring for our future*

From children and young people with learning disabilities, communication impairments and high support needs, and their families/supporters

Question 1 – Quality of care

How could care be better?

How could people who provide care be trained better?

Write your answer here

Care and support needs to be family-oriented from the start when dealing with children and young people

Every member of the person's immediate family should be taken into account, and their needs should be looked at as part of the whole situation.

Being a lifelong carer needs more recognition – people with learning disabilities need support from the cradle to the grave.

Getting the assessment right in the first place is really important – and reviews must be high quality, regular, and followed up with resources as needed, not "if available"

The continuous cycle should be Assess -> Respond -> Review

Social workers need better training, more time to spend with people, and they need to focus on the person, not on the potential costs. They need to understand that they have a legal duty to people, not budgets.

The role of "care manager" should be fulfilled by staff qualified in social care or a closely related discipline, and never by unqualified “senior practitioners”

Social workers need to know that people expect person-centred approaches now – it should not matter how long ago they were trained!

Adhere to the UN Convention - Our obligation is to work towards ‘achieving progressively the full realization of the rights of these people’ (Raising Our Sights statistic- in a population of 52 million 16,000 adults have profound intellectual and multiple disabilities). Given this is a very small group and they are totally dependent on others for their life, death and opportunities available - the financial imperative should be second to individual need - **unless the state acquires failed state status**. Currently financial imperative is paramount and this cannot always be the case. Safeguards to be in place to guard against wastefulness.

“Best Interest” support and opinions to be developed to include a whole society approach to the most vulnerable - an expectation of a legal duty, a financial duty and an **essential culture** - at every level - from individuals, companies, local authorities and the nation state. With clear strong leadership from our democratic representatives. This most vulnerable and complex group is very small. They are the group of people who realistically rely on others to support them to advocate and meet all their daily needs. The concept of best interest to cover health and social care and include emotional, intellectual, psychological, social and physical wellbeing. All to be delivered in a manner that is dignified, promotes independence, maximises potential and is inclusive and person centred.

Put in place a clear legal framework which makes the LAs and other agencies’ duty to *people* higher than their duty to a budget. Independently inspect all areas of adult social care decisions and provision including assessments and reviews.

Question 2 – Personalisation

How could we give people more choice so that they can choose the type of care that is best for them?

How can the benefits of personal budgets, including direct payments, be made available to everyone who gets support from social care.

Write your answer here

There is confusion, many different interpretations, about how personalisation works – particularly around Continuing Health Care and Personal Health budgets – people are being told there is a shift away from the Medical Model, as if that means they shouldn't ask for NHS-funded support! So there should be an expectation that all services use a social model approach, to avoid confusion between an approach and a cost centre.

People are rarely given all the possible choices – the care or support offered depends more on what is available, rather than what is best for people.

Advocacy is really important to enable people to get the support they need, but what if that advocacy is funded by the LA – how is it then independent??

Personalisation is about supporting ordinary lives.
Getting joy out of your family, finding ways to appreciate time with them

Professionals need to be trained in what personalisation actually means – lots of them don't seem to get it!
THIS ENGAGEMENT EXERCISE PROBABLY DOESN'T ASK ALL THE RIGHT QUESTIONS, SO WE HAVE SIMPLY MADE

OUR OWN COMMENTS!!

Question 3 – Shaping local care services

How can we make sure there are lots of local organisations which can provide different types of care?

Write your answer here

Involving people from the start in defining the support and services people need.

Creative alternatives are needed, not just more of the same, done in a different place.

Seeing beyond the provision of personal care – people want a life, not a service.

Small, inclusive, diverse providers offering wider choice – it’s about how things are commissioned – what’s easy for the LA is not necessarily what people want, so people and families should be participating in making those “hard choices”.

Monitoring how the money is spent is important to ensure quality - what proportion goes on direct care, and what else does it go on?

Need support for more social enterprises, mutual societies, co-ops etc. to develop – put people before profit.

If people cannot be supported properly by staff in hospitals because they are not trained or experienced in multiple needs, then ask family members for suggestions and help, and acknowledge that doing this is a positive support to the person – don’t let professional job-titles and demarcation prevent delivery of high-quality, dignified, personalised care and support.

Question 4 – Prevention

How can we stop people's health from getting worse and help them to look after themselves for longer?

What kind of support helps people to keep living a good life and to avoid becoming unwell or having a crisis?

Write your answer here

Ensure that regular health checks are done, and offer advice about maintaining healthy lifestyles – make sure that health checks result in health action plans being drawn up for people, even if only to encourage maintenance of good health.

Contingency planning is really important, so that when things go a little bit wrong, people don't then fall into a sudden vicious circle.

Integrating services so that people are treated holistically, and don't get even more stressed by what's supposed to help them!

Care/support workers to be better trained in healthy lifestyles - that are tailored to individuals needs and when necessary sufficient medical supervision in the community. E.g. dialogue between the person, diabetic nurse, the family and carers.

Apply MCA principles in a more individualised manner - both to the person and to the particular decision. Train and provide support more rigorously to meet the VPN definition of in control, the role of family in the MCA and the requirement for contingency even when capacity has been established.

Embed in training and application dignity and respect. Link to legal obligations around Human Rights UN convention - all aspects of the process/ service - strategic planning to delivery - include in ministerial responsibility.

Question 5 – Integration

How can we make sure the NHS, social care and other support services work more closely together to make things easier for people who use more than one service?

Write your answer here

Clear legal framework is needed to ensure accountability – no pointing at another body or organisation and saying they are to blame!

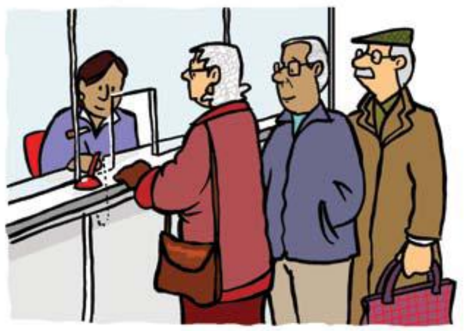
Transparency and open-ness about what can be done, not raising false expectations, but also acknowledging that services should try to do their best all the time!

Have champions for strong multi-agency working who celebrate examples of clear reporting lines and contacts.

Don’t hide behind Health and Safety or Data Protection worries – get it sorted.

Sort out flexible support for people’s discharge from hospital at the time they go into hospital, so they know what to expect, and it is planned ahead.

Local area agreements and joint improvement plans to recognise the role of the social model in health care (remembering that a model and approach is not the same as a cost centre) - have frameworks that encourage joint/multi disciplinary working - but keep integrity, dignity and respect within health - to prevent a solely mechanistic approach within the health service - dumping of responsibilities to other services under the guise of repositioning within a wider agenda of social inclusion - this will lead to more examples of people having to be prescribed water in hospital, being told they cannot have particular types of wheelchairs - that will prevent deterioration in someone’s body - because they are not disabled enough. Thus imposing deterioration and possible surgery because for some perverse reason - preventing deterioration is not a clinical reason - and other such nonsense.



Question 6 – The role of financial services

What sort of financial products and services would be useful for carers and people who need care?

Write your answer here

Fairer distribution of whatever financial resources exist would be a priority before this.

Carer providers to have families, self advocates and employees on boards and steering groups at all levels of the company/organisation and be obliged to show how they involve all parties. From local level to national company level. Good information to be made available for this - including financial information.

Percentage of profits allowed – this should be fixed in the contracts with providers – carers and individuals would have more faith in where the money is spent if this was transparent.

Top salaries to be transparent and simple to understand. Executives failing to deliver appropriate care to be removed without pay outs and to have legal responsibility for persistent gross failure of care. eg Winterbourne and Staffordshire Hospital

More transparency needed across the board.

Support and advice for people using personal budgets – independent brokerage should be an option within personal budgets everywhere.

Question 7

What do you think about the funding ideas suggested by the Commission on Funding of Care and Support (Dilnot)?

Write your answer here

Generally, agreement that ideas are sound and make sense – the cap on personal contributions at £35000 was particularly well-received.

People who have been disabled since birth should not have to fund any of their care.

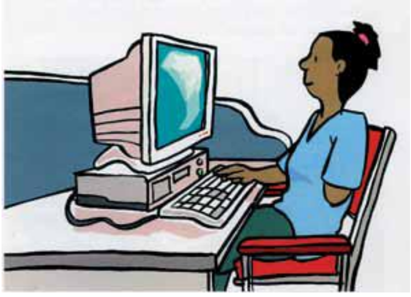
HOW TO LET US KNOW WHAT YOU THINK

- You can email us at **caringforourfuture@dh.gsi.gov.uk**

- You can write to us at:

Caring for our future Area 117, Wellington House 133–155
Waterloo Road London SE1 8UG

- You can give your comments on our website by visiting **www.caringforourfuture.dh.gov.uk**



Make sure you tell us what you think before

Friday 2 December

Caringforourfuture