

DOING THE RIGHT THING: PUBLIC ENGAGEMENT SPRING – SUMMER 2016

(Report on the face to face engagement conducted on refreshed policy: “Micro-Commissioning in Adult Social Care, Continuing Healthcare and Funded Nursing Care: Principles of Consistent, Pragmatic, and Ethical Decision Making For Staff”)



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Background to the Engagement

North East Lincolnshire Council (NELC) has delegated adult social care functions to NEL Clinical Commissioning Group (CCG) via a section 75 agreement under the NHS Act 2006.

Whilst CCG staff micro-commission continuing healthcare (CHC) and funded nursing care (FNC) support, micro-commissioning functions in respect of adult social care have been devolved primarily to various local community interest companies. Micro-commissioning is the commissioning of individual packages of care and support for individuals with eligible needs.

The CCG and NELC ('the Partners') work together to ensure that their respective contractual and statutory duties in respect of adult health and social care are discharged. The Partners wish to ensure that those micro-commissioning on their behalf discharge their obligations lawfully, and to assure themselves that such micro-commissioning takes place in the context of public awareness.

The refresh of the micro-commissioning policy, aimed at staff, has been utilised as a platform to promote better public understanding of how the money available for care and support needs is spent, create realistic expectations of the support available, and encourage planning for potential needs. In publically engaging on this policy ('the Policy'), the title 'Doing the Right Thing: Deciding how Social Care Money is Spent Locally' was chosen.

Approach to the Engagement

Members of the public have been engaged via a) an online survey and b) face to face via community groups and/ or specially arranged events. The results of the online survey have been analysed by an independent company, Eventure Research, within a separate report (see attached). This report focuses on face to engagement, but draws on themes across both methods of engagement.

Within this report, analysis of the face to face engagement will be approached by utilising the following five topics (abbreviated from those covered by the online survey):

1. Understanding of adult social care and support
2. Funding social care and support needs (including considerations of healthcare funding)
3. Importance of achieving value for money
4. Self-reliance and its implications (including the impact on friends and family)
5. Balancing value for money with outcomes

Methodology and Limitations

Community groups were invited to host a presentation via ACCORD and Healthwatch, and were therefore self-selecting. Limited offers to host a session were received. Between March and October, presentations will have been given to 10 community groups/ events, by a single CCG staff member. Around 180 members of the public participated in those events which took place prior to collation of this report (a further two events are scheduled). Nine staff sessions were undertaken, involving around 50 key personnel (then responsible for cascading messages to wider staff).

Stringent efforts were made to record comments and views as accurately as possible, but it was not always easy to take notes and facilitate conversation/ respond to queries simultaneously. A fuller selection of the comments provided (in so far as they were relevant to this engagement), are provided on pages 6 to 9. Where the same comments were repeated across different groups, they have only been included once, to avoid repetition.



Understanding of adult social care, and the distinction between health and social care

The online survey results indicate an overall good understanding of the distinction between health and social care. The majority of respondents to the online survey were ACCORD members; other contributors may well have been Healthwatch members. Members of ACCORD and Healthwatch are more likely to have a greater understanding of health and social care than the wider public.

Face to face engagement revealed a correlation between understanding of the health and care system and the level of participation in it. This applied to community groups and individuals; i.e. those who had called on the system (for example to secure social care for an elderly relative) had greater knowledge than those who had not. As a participant commented “People don’t understand or think about the system until they or someone they know needs it”.

It is perhaps telling that whilst most older people recognised Bevan (depicted in the powerpoint presentation delivered), most hadn’t heard of the Care Act 2014 - which recently consolidated the foundations of the welfare state laid by Bevan. Overall, understanding of how to access healthcare was clearer to participants than how to access social care. As a staff member noted, “everyone goes to their GP because they don’t understand the system”.

Some felt that the distinction between health and social care was artificial, arbitrary and unclear, especially for example, for those with dementia (because a dementia diagnosis does not mean an individual automatically qualifies for CHC funding). A number felt that the distinction was one that staff working within the health and care system found difficult to navigate, and that navigation was inevitably more difficult for members of the public who were often “totally confused”.

It was clear from participants and staff that limited understanding of the difference between health and social care created an expectation that both are free at the point of delivery. Where people were aware that they may have to pay for social care, a common concern was that the value of their home could be utilised to meet costs. One participant stated “the conversation on social care needs often starts in hospital or with GPs and the split between free and non-free services is therefore unclear. The conversation is begun with those who have not got the ability to implement any of the social care [i.e. health care staff] or perhaps know all about it. Mixed messages are given”.

Summary finding: the complexity of the system creates a barrier to understanding, and therefore to access. If people don’t know how to access support, they may fail to do so until a crisis precipitates it. This creates unnecessary distress, increases costs, and undermines the Partners’ prevention agenda. Raising awareness of the local system and where to go for help is crucial.

Understanding of, and views regarding, funding social care and support needs

The online survey results show that 61% correctly identified access to social care as means tested, but 17% believed it to be free to those with eligible needs through taxation and insurance. Face to face engagement highlighted that those with less experience of health and social care were even less likely to be aware that social care is subject to financial assessment.

Face to face discussions around means testing tended to focus on what people felt to be their reasonable entitlements; a number commented that the “baby boomer generation” had paid into the system for years, with an expectation of receiving support. Some were now discovering that that support is not available to them without a further financial contribution, and they felt that this was unfair: “Older people who have carefully monitored their financial resources over their lifetime are penalised” i.e. they should have “blown their money while they could enjoy it, and avoided paying for their social care”. Some staff expressed concern that this sense of unfairness was resulting



in financially-motivated refusals to accept care, which later creates unnecessary admissions to hospital, i.e. people refuse care because they don't want to pay, and so go into crisis.

Conversely, there was understanding that "we can't spend what we haven't got" and support for the proposition that "if people have the money, they should pay for care". One participant noted that "People have expectations which are far higher (and expectations are getting higher) than what is on offer". There was some debate around whether expectations were generational: "Younger people have much higher expectations of what the state will provide than older people, who expect to have to do more for themselves and don't necessarily like to ask for help".

Comparison between individuals in apparently similar circumstances resulted in frustration: "People are angry/ dissatisfied when comparing their own situation [if they are ineligible for help] against their neighbour's situation [which appears the same, yet is eligible for help]. The costs of supplying your own care needs are high, when you can get no or limited help". There was some feeling that if charges were to be levied, they must be applied to all equally: "the issue is chasing debts for those who can but won't pay (including those hiding their funds). We should chase debts".

Some commented on the partly subject nature of eligibility: "assessing real needs not wants is important, but different organisations treat an individual in different ways – subjective assessments are dependent on the person assessing". One participant suggested that "staff are pressured into not spending money, and so cost shunting goes on between health and social care". The anxiety about funding constraints which is inherent in this comment was not uncommon: "people assume they'll be ok [if they ever need help] but negative media stories raise awareness of difficulties we could face in future; makes you stop to think about what'll be on offer in future".

Summary finding: the conflation of the health and care system creates an expectation that all support is delivered free at the point of access; thus, interactions with social care staff often begin with disappointed expectations which can lead to disillusionment and complaints. Equitable application of a clear charging and resource allocation policy across all relevant partners is key.

Value for Money

The online survey results show that 96% of respondents considered value for money of importance (68% very important and 28% somewhat important). Across face to face engagements, use of the National Audit Office's '3 Es' to secure value for money was universally endorsed; however, similarly, to the views expressed online, there was concern that the pursuit of value for money should not compromise quality of care.

To support face to face discussion around the difficulties of allocating resources, a case study was used - that of Elaine McDonald, also referenced in the Policy. This case provided a useful example of how budgetary constraints could apply to an individual: the view amongst participants that Elaine McDonald was badly served (in being obliged to rely on NHS-provided incontinence pads instead of support from an overnight care worker) was widespread. However, the way in which the European Court of Human Rights balanced individual need with preservation of public budgets, secured a measure of understanding: "My father has incontinence pads and Kylies; Elaine's position isn't as bad as it sounds"; "Elaine should at least have tried the incontinence pads". Responses can perhaps be summarised as sorrowful acceptance (not necessarily agreement): financial constraint necessitates difficult decisions, which can sit uneasily with conceptions of dignity and wellbeing.

A participant questioned whether we should "explain to people how much the services they want/ use cost, so people value these. There needs to be communication with people to explain the difference between wants and needs". Others noted that the way in which a reduced or refused



offer of support is communicated is fundamental: “professionals need to be conscious that removal of something that a person has no eligible need for might feel to that person like the removal of a lifeline. Therefore professionals can’t just take it away and leave the person and expect them to be okay”. “There is a skill to explaining a refusal”.

In discussing how value for money criteria could impact on individuals, some raised concerns about the wider commissioning of services: “achieving value for money and/ or rationalisation of services on a larger scale isn’t always achieved”; i.e. it was not always evident that the same principles were applied to commissioning for the population as are applied to micro-commissioning for individuals.

Summary finding: expectations of state-funded provision are often high, but there is belief in the importance of securing value for the ‘public purse’. There is work to do in creating realistic expectations of state support. Evidencing that commissioning and micro-commissioning decisions are made on the basis of rational and reasonable principles (including value for money) is crucial.

Self-reliance and its implications (including impact on family and friends)

The online survey results show that 99% of respondents considered encouraging self-reliance to be of importance (83% very important and 16% somewhat important). The results also show that 100% of respondents said that it was important to consider the impact that an adult’s needs may have on others around them (89% very important and 11% somewhat important).

In the context of face to face engagement, taking an asset-based approach to working with individuals was discussed, alongside consideration of what else other than commissioned services might support an individual (including calling on their family or community).

A common view amongst participants was that “it is reasonable to expect people to do as much for themselves as possible” but that the state should still “provide for those who need it”. The views evidenced within the online survey were reflected by one face to face participant: “in the case of older people degenerating rapidly it is unrealistic and unfair to expect these conversations on wise/ good/ better value ways to meet need. It is unfair to expect people in this situation to be able to help themselves. It requires a lot of skill for professionals to have these conversations [focusing on assets and strengths] and they are not always skilled appropriately”.

Similarly, in discussing the whole family approach espoused by the Care Act, one face to face participant stated: “having conversations about balancing the needs of both the carer and the cared for is not always easy; many service users may be isolated and not have family, and some that do may have needs which contradict each other”.

Other face to face participants noted that “people’s families should help if they’re able” and “we don’t look after our own anymore and we should do”. However, a recurring concern was that not everyone has family or others around them to support self-reliance. Some raised specific concerns around the ability of the wider system to support self-reliance, for example: “support on discharge from hospital is inadequate; this needs to be considered if people are expected to be self-reliant” and “a major factor in social care is housing, which has deteriorated in the last 30 years; good housing would reduce a lot of problems [and promote self-reliance]”.

Summary finding: self-reliance (where safe and appropriate) is positive but cannot replace state care for those who need it: it must be supported by provision across the wider system. Confidence in an approach which promotes self and community reliance can be increased by developing confidence that the system provides a genuine ‘safety net’ for those in need.



Balancing Outcomes and Best Value

The vast majority (99%) of online respondents said that balancing value for money with the results that matter to those with needs was of importance (73% very important and 26% somewhat important). This was similarly important for a majority of face to face participants, although some challenged the extent to which current processes support a focus on personalised outcomes, noting that application of eligibility criteria can feel like “a tick box scenario which was very unhelpful”; “social care is still not person centred, taking a one size fits all approach”.

Another participant suggested that personalisation could be achieved by supporting “more flexibility to allow people to pool their personal budgets and maximise shared outcomes”. One suggested that there could be conflict between carers and cared for persons being able to choose how to spend their budget to deliver the outcomes that matter to them, and professionals being unwilling to allow them that autonomy. It was suggested that social workers “come out of university without hands-on experience” and don’t always have the skills to facilitate difficult balancing exercises.

Many conceded that there were tough choices to be made by care practitioners in allocating resources. A number of participants indicated that they would find it difficult to have conversations with individuals – like Elaine McDonald - which resulted in them receiving less than hoped for.

Summary Finding: there is understanding of the balancing exercises required of care practitioners but less confidence in their ability to conduct them. Tolerance of decisions which prioritise financial considerations over individual outcomes may be limited without carefully reasoned justifications.

Conclusion

The majority of face to face participants genuinely engaged in debating the Policy’s implications. Although some were positive in their assessment of the health and care system “we are lucky in the UK, we do still provide a lot of support for those in need”, others were more sceptical “the CCG is being asked to work with a budget that’s impossible/ has been set an impossible task. The NHS is under-funded and ‘wants’ are being expanded which can’t be met. Everyone wants utopia; it’s not been costed and is unrealistic”; “If we want ‘free’ we’ll have to pay for it”.

Overall, participants indicated that in the current context, the approach proposed by the Policy had merit, namely: securing value for money, focusing on assets and strengths before considering an allocation of resources, the relevance of wellbeing and the whole family approach, and balancing outcomes and best value. However, this endorsement did not remove concern that decisions taken in the context of limited budgets could result in unpalatable results for some individuals. Agreement to principles in abstract is not necessarily a reliable indicator of responses to actual decisions. Challenges to the Policy may be expected where individuals receive less than desired; challenge is best combated by evidence that consistent decisions are taken in accordance with the principles set out in the Policy, which effective, reasonable and appropriate.

Staff commented that the principles within the Policy are already followed, but felt that perhaps historically, some staff haven’t been good enough at taking cost into account. One staff member noted that the Policy’s approach “represents a major behaviour change for society; we will only change behaviour by drastically reducing what is available”. Against this backdrop of public expectations, some participants stated how useful the discussions had been and how much they had learned about the health and care system, but – “how do you reach those that don’t come to clubs like these?”. This encapsulates our greatest challenge: if we are to change expectations, understanding and behaviour, how can we best reach people? This challenge of raising awareness and removing barriers to access should be addressed via commitment to the developing health and social care information and advice strategy (due to launch from April 2017).



Next Steps

Effective implementation of this Policy requires:

1. A robust and on-going programme of staff engagement to ensure that the principles within the Policy are being adhered to, and decisions made in accordance with it are well evidenced
2. A responsive, integrated information and advice strategy to inform and engage the citizens of North East Lincolnshire in a way that will clarify and manage expectations



Summary of some Comments made during Face to Face Engagement

Understanding of social care and support

- People don't understand fully how it has all been brought together. Professionals don't link up between health and social care
- Professionals don't recognise or clearly grasp the link up/way it feeds in. The general public is totally confused.
- Many people don't understand where to access support, especially in respect of social care
- The conversation on social care needs often starts in hospital or with GPs and the split between free and non-free services are therefore unclear. The conversation is begun with those who have not got the ability to implement any of the social care or perhaps know all about it. Mixed messages.
- It is reasonable to address real needs and not wants. If people need funding, one professional could do the needs assessment and also the financial assessment to ensure continuity
- People felt that there was limited understanding that health and social care are different; many people have an expectation that both are free at the point of delivery. Most people don't understand the system until they need to call on it
- People do understand the distinction, and fear that their house will be taken away to fund their social care
- The distinction between health and social care is artificial, and is a distinction which is not made in other countries
- People don't understand or think about the system until they or someone they know needs it
- No one knows how to access help
- The two systems are interdependent even if separate
- People don't understand how to access health and social care or what's on offer; the system is extremely complicated
- Line between health and social care is arbitrary and unclear, especially (for example) in respect of those with dementia
- Access is hampered by a lack of knowledge and understanding about the system.

Funding of social care

- People have expectations which are far higher (and expectations are getting higher) than what is on offer. The truth of this is a very different story.
- Assessing real needs not wants is important, but different organisations will treat an individual in different ways – subjective assessments are also dependant on the person assessing
- People are angry/dissatisfied when comparing their own situation (where perhaps they are ineligible for help) against their neighbour's situation. Costs of supplying own care needs are high, when someone can get no/limited help
- If people have the money, they should pay for the care
- Sometimes those who are accessing care unfairly get caught as they are too greedy and are attempting to access even more care services
- Issue is chasing debts for those who can but won't pay (i.e. those hiding their funds). We should chase debts
- A charge is usually put on a house where there is a debt to pay and it's to be taken from the house once the person has deceased



- Younger people have much higher expectations of what the state will provide than older people, who expect to have to do more for themselves and don't necessarily like to ask for help
- Older people have paid into the system all their lives and are entitled to expect something from it that is delivered free of charge
- Cost shunting goes on; staff are pressured into not spending money, and so cost shunting goes on between health and social care
- What people get charged depends on the staff member
- State-provided social care didn't meet my expectations; I had to pay privately to get help I was happy with
- Can't spend what we haven't got
- Older people fall into two categories - "I've paid in so I'm entitled" v "I don't like to ask for help". Young ones expect everything.

Planning for future needs

- Older people who have carefully monitored their financial resources over their lifetime are penalised i.e. they should have blown their money while they could enjoy it, and avoided paying for their social care
- We've paid all our lives; we're entitled to expect the system to give back
- People assume they'll be ok [if they ever need help] but negative media stories raise awareness of difficulties we could face in future; makes you stop to think about what'll be on offer in future
- The more you give people the more they want
- We don't look after our own anymore and we should do
- Discussions need to start in schools, with education, regarding our expectations
- These are tough conversations that may impact on people potentially losing out. How the conversation is had is key. Advanced planning is required so it's not so much of a shock when the conversation is had
- The NHS has created expectations; people perceive health and social care as their right and it is difficult to dislodge this perception.

Achieving value for money

- Agree the 3 criteria to spending resource were good criteria
- NAO's 3 E's seem reasonable, and provide some comfort/ confidence that money is being well spent
- Consensus that NAO criteria was useful and appropriate/ seem reasonable/ sensible
- NAO criteria are useful, but could result in difficult decisions being made
- If it would help should we explain to people how much the services they are wanting/use cost, so people value these. There needs to be communication with people to explain the difference between wants and needs
- Professionals need to be conscious that removal of something that a person has no eligible need for might feel to that person like the removal of a lifeline. Therefore professionals can't just take it away and leave the person and expect them to be okay
- How news is delivered is fundamental. Elaine knew in her own experience that she couldn't have everything she was asking for, but there is a skill to explaining a refusal, etc



- Consensus initially that Elaine McDonald was badly dealt with – people understood the budgetary constraints but felt that being asked to put up with continence pads was undignified. Later people reiterated their understanding of the budgetary limits, but felt sorry for Elaine
- All accepted that there were financial constraints and that difficult decisions have to be made on how to share resources fairly
- Initial widespread support for M; on considering court judgement, both perspectives were understood: “Elaine should at least have given the continence pads a try” Universal view that Elaine should continue to be supported by night-time care workers
- Achieving value for money and/ or rationalisation of services on a larger scale isn’t always achieved (i.e in the wider commissioning of services); the same principles should apply to commissioning for the population as applies to micro-commissioning for individuals
- Everyone want’s money; Elaine was wrong to expect such costly care
- My father has continence pads and Kylies; Elaine’s position isn’t as bad as it sounds
- Elaine’s social needs must be considered as well as her physical needs
- It is undignified for Elaine to be expected to use incontinence pads
- Agree budget holders have a responsibility for carefully managing public funds and ensuring that there is enough to go around.

Encouraging self-reliance

- Social prescribing needs to “step up” and take a part in better use of resources.
- These conversations felt like going back to how things were before. But the issue is always in how we find those who genuinely need the help
- Agreement that personalised, asset-based approach is appropriate, along with balancing outcomes and best value (subject to below concerns)
- Expectations of self-reliance, to some degree, reflect a return to before the creation of the welfare state
- We’ve become too reliant on the state; we’ve become lazy and over-demanding
- The state should provide for those who need it
- Its positive – but could result in difficult choices being made
- My experience was that everything seemed to be not the responsibility of the domiciliary care agency provided by social services, so I went private. I then did get the help I needed, but what about those that can’t afford to pay?
- It is reasonable to expect people to do as much for themselves as is possible
- I had a good experience of hospital care, and staff who ensured I had support at home before discharging me.

Implications of self-reliance including impact on others

- In the case of older people degenerating rapidly it is unrealistic and unfair to expect these conversations on wise/good/better value ways to meet need. It is unfair to expect people in this situation to be able to help themselves. It requires a lot of skill for professionals to have these conversations and they are not always skilled appropriately
- Social care is still not person centred, taking a one size fits all approach
- Not everyone has anyone to call on for support



- A major factor in social care is housing, which has deteriorated in the last 30 years; good housing would reduce a lot of problems. Challenges of self-reliance – living in an setting unsuitable to needs.
- Support on discharge from hospital is inadequate; this needs to be considered if people are expected to be self-reliant
- Having conversations about balancing the needs of both the carer and the cared for is not always easy; many service users may be isolated and not have family, and some that do may have needs which contradict each other
- Balancing wellbeing of individuals with needs and those around them/ the whole family approach is welcomed, but not everyone has people around them offering support
- People's families should help them if they're able.

Balancing Outcomes and Best Value

- An important consideration
- Reasonable consideration
- Criteria for eligibility felt to me like a tick box scenario which was very unhelpful – concern that personalisation is inadequate
- Social workers come out of university without practical experience and therefore don't always have the skills to facilitate these conversations
- There needs to be more flexibility to allow people to pool their personal budgets and maximise shared outcomes
- There are issues therefore with carers and the cared for being able to choose how to spend the budget (when the choices are appropriate) verses focus refusing to allow that spend
- Some understanding that there are tough choices to be made by social workers in allocating resources in cases like Elaine's.

General

- All of the considerations discussed seem reasonable in theory but don't always work like that in practice
- All of the considerations discussed seem like a good place to start
- Many would not like to be having these discussions with individuals, especially if they resulted in individuals receiving less than expected/ less than previously.