

Joanne Twomey

From: Joanne Twomey
Sent: 07 October 2016 16:07
To: Joanne Twomey
Subject: RE: Proposals for Reductions in "Community Life Choices" and Special Category of Learning Disabled

From: Clive Hadfield
Sent: 06 October 2016 16:28
To: Joanne Twomey
Subject: Proposals for Reductions in "Community Life Choices" and Special Category of Learning Disabled

Dear Ms. Twomey,

Thank You for your e mail, yesterday. Please will you circulate this response to Cabinet Members?

This is about the proposal to reduce "Community Life Choices" (day care provision) for all Users, including Learning Disabled. On behalf of our sub Group, I have summarised points to keep it as brief as possible.

Learning Disabled Users have not been specifically mentioned in the Summary Report. Extrapolating from the Councils own figures: Only 4% of Council paid residential care users are Learning Disabled AND about 50% of day care users are Learning Disabled. So, it is unlikely that the application of either proposal (withdrawal of day care for funded residents and a 4% reduction in days of day care provision) to Learning Disabled Adults will lead to any worthwhile financial saving, particularly when set against likely problems arising from the Learning Disabled minority.

It is an error to include Learning Disabled within general expectations of disability as a whole. Learning Disability is different because:

Unlike many other disabilities, it is usually "whole life" "cradle to grave" "70 years plus" and "without prospect of improvement".

Unlike many other disabilities, Learning Disabled Adults must have social and intellectual stimulation daily, to compensate for the effects of Learning Disability.

Our sub Group suggests that Learning Disabled Adults should be exempted from these proposals.

As a result of the consultation, the Family Carers sub Group of the Learning Disability Partnership Board grouped their experienced responses under six headings:

The Quality of Consultation, including publicity and timing

An objection to Q10. Presumption of Family willingness to take on extra duties – may not comply with Care Act.

Restricted reply choices.

Limited calendar time and limited circulation.

The legality of top down policy requirement applying to all person centred (outcomes focused) individual cases

Each Learning Disabled Adult should have an outcomes based, person centred assessment. For LD Adults, there should be minimum change over many years

Each honest Assessment is based on meeting need, not finance. Obviously, need must be met economically. See item six.

The unfairness of equating long, long, long term disability living needs for stimulation (social, artistic, intellectual, etc.) with the shorter term needs of other disabled persons who do not have the deprivations of learning disability. Unstimulated LD persons are likely to become difficult, leading to Winterbourne methods of control or expensive hand back from un coping private providers to the Council.

Care is more than food, shelter and sanitary accommodation. Sitting down quietly and looking at the walls is not enough!

The bad economics of expensive LD re assessment reviews, with more than one purpose, and the minor cash cuts likely to be generated, giving very poor financial pay back.

Those LD with moderate needs have already had their support withdrawn. So, the major cost cut has already been made. Only difficult LD cases remain, with little realistic prospect of significant cost savings.

Increased demands on the elderly Carers of LD Adults is likely to lead to Carers inability to cope with the added demand and, so, responsibility is likely to transfer to Council at Council cost. Very few LD Adults have any money in their own right to pay for care.

The co ordination of days and weeks of time periods. Benefits are paid on a weekly basis. Every week is equal to every other week. Some private providers have contracts for every week to be a paid week.

Providers fixed costs continue for all weeks. Thus, the same costs must be recovered at a higher weekly rate over fewer weeks.

Some providers are providing valuable free services to the Community. These services may be invisible to the Council but, if withdrawn, would appear as new cost to the Council.

Pointing Out The Obvious Wastes. Every Carer can point out wasteful practices and arrangements. Just ask the Carers to point out the potential savings.

A forwarded e mail follows. It points out lots of potential cash savings.

The sub Group hope this is helpful to the Cabinet AND that the Cabinet will wish to exempt Learning Disabled Adults from the proposals.

Clive Hadfield

Chairman, Family Carers sub Group of Leicestershire Learning Disabilities Partnership Board.

From: Clive Hadfield

Sent: 12 September 2016 17:18

To: 'Amisha Chauhan'

Cc: Jane Robins ; Gill Huddleston ; Linda Wright ; Lyn Spence ; R. A. J.....

Subject: Point No Six - Pointing Out the Obvious

Dear Amisha,

Thank You for your response to the six points about the consultation on Day Centre cuts. This response to your response concerns item six (obvious wasteful arrangements and practices at an individual level).

Obviously, Question 12 on the Consultation Document is not an appropriate place to set out one off individual examples of Council Waste. This points up the Council's expectation of top down, "blanket", "one size fits all" solutions when, in fact and with due diligence, almost every individual case could raise an individual saving. Each saving would be

particular to that case. All the specific "one off" and individual savings would aggregate to a substantial money saving overall, and without the social damage of the top down imposition of an ill considered and blunt policy.

In our own case, I have pointed out very obvious and large financial waste to very Senior Officers on four occasions. Nothing has been done to effect the savings. Here follows a catalogue of Council Waste and Error, centred around one individual:

Public Resources Ignored

Three Councils (County, District and Town) have several buildings in Lutterworth, which are suitable for day centre use, at NIL cost to the overall public purse (Public body to Public body transfers may be ignored if the Public bodies are serving the public overall). Also, there are Churches offering free or low prices accommodation, as part of their Community Service.

Similarly, the Councils offer educational and recreational activities which, if freely offered to Learning Disabled Adults, would provide many of the necessary stimulæ at a potential overall saving to the public purse.

Poor Contract Arrangements

When there was a day centre activity in Lutterworth, The premises contract was fairly expensive. The landlord abused the use of the premises in many ways and, so, it was bad value for money. When the Lutterworth day centre was disbanded, the landlord levied a £10,000 contract termination charge onto the Council.

Refusal to Accept Money

Waitrose at Lutterworth offered about £400 to the Learning Disabled Day Centre Group at Lutterworth. The Council refused to accept the money on the grounds that "There is no mechanism to accept the money".

Destruction of Local Links

The main activity of the twenty or so Learning Disabled Adults at the Lutterworth Day Centre was the preparation and presentation of two concerts per year. The activity was very low cost/no cost. Individuals did singing, dancing, readings and mini sketches. The concerts were very much appreciated by the local Community, until the Council stopped them.

Set up Large New Transport Costs

The twenty or so Learning Disabled Adults, who attended at Lutterworth, had either nil or very low local transport costs. The dispersal, mostly to Market Harborough, has incurred lots of new individual transport costs. I guesstimate the added transport costs as between £50,000 and £100,000 pa.

Inefficient Individual Transport Arrangements

The distance between Lutterworth and Market Harborough is 14 miles. To transport one individual by taxi from Lutterworth to Market Harborough requires a taxi mileage of 112 miles per day, under the arrangements made by the Council. That individual has a "one to one" supporter, who is an authorised car user. The supporter could meet some of the transport needs at a much lower daily distance and at a much lower cost to the Council.

Rules Stop Common Sense

The Lutterworth Individual would like to attend a private day centre in Lutterworth for one day per week. That would exchange 112 miles of taxi costs for a return bus fare between Harborough and Lutterworth for the necessary and established "one to one" supporter. Unfortunately, the trusted "one to one" supporter is contracted to the Council's Roman Way Day Centre in Market Harborough. There is a Rule that the trusted contracted "one to one" supporter cannot accompany the Learning Disabled Individual to a non Council Day Centre. So, the wishes of the Individual Learning Disabled Adult cannot be met AND the Council cannot make a cash saving.

I hope that the Council will reduce it's "telling" and take up more listening. There are cash savings to be made by attention to detail at a practical level and as understood by Carers.

Regards

Clive Hadfield

Joanne Twomey

From: Joanne Twomey
Sent: 11 October 2016 11:42
To: Joanne Twomey
Subject: FW: notes to cabinet re community life choices
Attachments: 20160111_Consultation_principles_final.pdf; To all of you who cared for me.docx

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From: Sara Brennan
Sent: 11 October 2016 11:28
To: Joanne Twomey
Subject: FW: notes to cabinet re community life choices

Sara Brennan
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From: Clare Clarkson
Sent: 10 October 2016 22:23
To: Mr. N. J. Rushton; Mr. J. B. Rhodes; Mr. R. Blunt; Mr. D. W. Houseman; Mr. J. T. Orson; Mr. P. C. Osborne; Mr. I. D. Ould; Mr. B. L. Pain; Mrs. P. Posnett; Mr. E. F. White
Subject: notes to cabinet re community life choices

Dear Cabinet Members.

My name is Clare.

I am writing to all of you directly out of concern with regards to the Community Life Choices Consultations findings and its proposals for which you will all be deciding its outcome.

I feel I have a moral duty to express my concern for those which will be directly affected. I also feel I need to ensure that you are given full insight from a different angle other than those presented to you on paper, before any implementation is approved at tomorrow's Cabinet meeting.

I feel that the papers lack emotion and there is little insight into Learning Disabilities and what it is like to be a person in a world always against you. So I write this as a person with not just politics and money saving agendas in mind, nor as just a person in employment within this sector, but as an ordinary person who has concern and empathy for family, providers and carers and most importantly my friends, otherwise known as Service Users.

I have attached a poem for you to read which is very powerful. It is written anonymously

I hope that you will take the time to read this and digest its contents.

Department of Health definition

In Valuing People (2001) they describe a 'learning disability' as a:

- significantly reduced ability to understand new or complex information, to learn new skills
- Reduced ability to cope independently which starts before adulthood with lasting effects on development.

(Department of Health. Valuing People: A New Strategy for Learning Disability for the 21st Century. 2001).

It is a fact that many people with a Learning Disability have very little understanding of information presented to them either by written or verbal methods. Many cannot speak, many cannot voice their concerns, and many do not have the capacity to understand complex information and cannot express feelings and thoughts for themselves.

My first question to you is: How much do you think this consultation has been made sense of to the people it affects most?

The facts are that many people do not understand change, what a change means, or how to adapt to change until the change has happened. Consequences cannot be considered as consequences are not understood. Therefore it makes it very difficult to have a traditional consultation delivered which it was, and for the facts to be as they are as real accounts for those taking part. The consultation process is clear. In accordance to your Consultation Principles; 2016 (which I have attached) It did not appear to have been adapted to the target group sufficiently, it ran throughout the summer, although extended as parents, carers requested, few providers circulated it, many parents were not informed and few Service Users attended.

However, the facts are clear. **The percentage of those against the changes outweighs those for the changes yet you have still received a recommendation by Adults and Communities to go ahead with the implementation??**

Ineffective consultations are considered to be cosmetic consultations that were done due to obligation or show and not true participatory decision making.

I question you as to the statement above being the fact of the matter. I feel it was a process and the decision is already based on money saving tactics rather than the results from the consultation with no regard to the serious impacts and detrimental effects upon those who the consultation was targeted towards. If this is approved, then what was the point in the process anyway?

I would like to make reference to : No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions. Introduction: the same real life as any other member of the community and an end to institutional care by default 15 and also Valuing People

" We hear too often from families of a pervasive culture, just as that highlighted by Sir Robert Francis,⁵ of failures to listen to people and their families and to treat them as people who hold expertise and who have the right to be in control of their own lives. We are seeing services and systems default to what can in effect be re-institutionalisation, either through lengthy inpatient stays or residential care against people's wishes. 4. Since at least the 1950s, it has been a key goal of public policy to bring an end to institutionalisation as a model of care for disabled people. The asylum movement of the Victorian era set in place a model of care for disabled people, in particular, those with learning disability, autism and mental health needs, which meant they were set apart in physically and socially isolated settings. This institutional model excluded people and enabled poor care and sometimes abuse to flourish. There has been substantial progress in shutting down such institutions over the last 40 years which should not be forgotten: • The asylums have been closed: in the 1950s, there were over 150,000 residents in asylums (with a mix of physical and mental health problems and disabilities). The last asylums were closed at the end of the 1990s.

I feel along with many that the result will be a repeat, modernised in ways that the system can cover it up to make it acceptable for this to again happen in today's society. A new style of Mini institutions will be created as each residential home struggles to meet the needs of their residents. Each home which is already funded to provide day time activities, struggles to meet the basic needs under the current settings. Often understaffed, over stretched giving little input, residents living together 24/7 is a recipe for disaster. In reality, only the homes which are proactive and honest will have their resident's best interests at heart. The others which are the majority will not.

It is a fact that Service Users who access Day Services are less likely during their time away from their living environment, likely to display challenging behaviour in Day Service settings. We see this time after time, with good cause. Day services were designed to specifically meet the individual needs of its users. Day services were invented as part of a modernisation strategy which over years and years of hard work, introductions of new legislation, policy's, better understanding, clearer ethics, The Care Act, The Equality Act 2010, Equality and Human Rights Act. Personalisation and support planning?? I've been directly involved in its implementation and how amazing it was, for a little while. But what is the point of all that lovely speak when in reality, what does it matter what a service users aspirations are when all that is seen firstly, are pound signs. Service users have no rights, if they did, then all service users would have their own money and chose what to do with it, where to go for services, where to live and chose who to support them. Not what fits into the system based on eligibility criteria? My point being, reality is far from the achievability of each comment made, each action point, each target and timescale set. It has been put in the consultation report to justify what money saving can be achieved without cause for concern. I argue as do many against it. To have all clients promised a full review of their needs, to include their circle of support, other providers, social workers, reviewing officers who do not know the person, would need several reviews to ensure the residential homes can meet needs. Not just one. The current review system fails our friends all the time. People are lucky to get a call from a review officer yearly. Reviews do not happen, when they do, it's by a stranger making decisions based on money, not need/ likes/ dislikes/ wants or choice. It frustrates parents, carers, and causes great amounts of stress and upset. A fact is- Often parents are bamboozled or lead to believe they are not entitled to this, not eligible for that, papers are given to them which they don't understand, they are not informed of their rights, nor the rights of those they love. Advantages such as these within the system can make a review seem daunting, pointless, and disregarded. Therefore, parents/ loved ones give up trying. They have often fought all their life to get their son/ daughter the best they can; they are tired, upset, and confused- now worried where their son/ daughter will, "end up". The whole review system needs to be revamped regardless but especially before any reviews are held with regards to this proposal. You can write as many action plans, aims objectives, you can by the use of terminology make things appear rosier, a better way of doing things, yet if you familiarise yourself with actual providers and organisations and most importantly the service users, we know, that as with many things, they are not worth the paper they are written on.

This particular read I found most disturbing.

6 Emerson E. An Analysis of NHS Long-Stay Beds and Residential Places for Adults with Learning Disabilities. (2003) Lancaster University. 7 Learning Disability Services Inspection programme: National Overview, Care Quality Commission (June 2012). 8 In this report 50% of facilities inspected failed some core standards on care and welfare – including protecting people from abuse. Only 14% of people were in fully compliant settings. 9 See, for example, Learning Disability census, England 2014, Health and Social Care Information Centre (Jan 2015) which showed on census day patients had an average length of stay of 547 days and were staying 34.4kms from home.

Introduction: the same real life as any other member of the community and an end to institutional care by default
15

"We know that in some settings levels of medication, restraint, and self-harm are high. Sadly, we also know of a number of deaths.10"

On the other hand, we have this beautiful picture of everything being ok. Really?? How. How can you suggest that any of this will happen when you take people away from the community? People do not have control over their finances. People's friendships will be long gone; families will be burdened into helping because there's no option. Times of Crisis will increase for both family and the service user. With the extra pressures to support their (still children) will be expected.

It is disgraceful to think that someone is paid to develop these strategies without fully understanding the reality of their proposals.

28 years of knowledge and experience in social care leads me to think that paper exercises are more important than the people they are intended to help. What in reality is needed is more money for residential homes to accommodate what is expected of them. In reality, someone who is on the " Shop floor" should be involved in your cabinet meetings. How many of you on the board have had the pleasure of working alongside someone with a learning disability? Have any of you had to go through a system with your son or daughter? Or do any of you have a learning disability? I doubt that very much, yet as part of the Whole Life Disability Strategy, employing a person with a Disability is part of the recognised development process which has been identified as important.

Yet answer me this.

How can someone with a learning disability find work without support? Residential homes **will not** have the time. Day services will no longer be an option. The residents will have no money to buy their own support, so that leaves those in supported living who can have control of their life and may have presented to them the opportunity. How can that be justified and fair? That is penalising those in residential care homes who are not eligible for Supported Living either due to availability or down to eligibility or simply down to money.

What rights do you feel you have as a Cabinet to take away choice, take away control take away opportunities? What rights do any of us have to disempower those who struggle to be heard? Those who cannot understand, walk, talk, shout, or cry? The friendship's made over years and years will go. What else can "we take away from the most vulnerable people in our society? It is a fact that this is not forward thinking proposals; this is a money saving exercise with a twist to make it sound acceptable by terminology such as this:

Increase independence? How? No staff, no money, no providers sustaining an income to offer opportunities.

Personal and skills development? I don't think so. In reality, most homes do all the cooking, all the cleaning, and very rarely have any skill development options available due to restraints. Most homes have everyone to bed at the same time; eat at the same time, even in 2016.

Community engagement? By whom? Again, that's what day services and PA's were created for, to do exactly that because residential homes cannot.

Health and wellbeing? Many people already have this at the forefront of their service delivery. When a resident is sent in with mouldy bread for a sandwich or yoghurt out of date, dirty clothes and unshaven, well I don't think wellbeing is evidenced there but it can be reported if seen. This is what happens in social care. This is what is getting missed. **THINGS ARE NOT REALITY, CHOICE IS NOT AN OPTION, HUMAN RIGHTS TAKEN AWAY**, and most of all the fact that only a few people which this will affect, makes it seem a worthwhile cause. Because it has happened elsewhere, makes it right? No, it doesn't.

I would therefore like to ask you on behalf of all those who were the majority to be against this proposal, to reconsider what else can be done to safeguard the wellbeing of those less fortunate than ourselves. For the council to reconsider its proposals and think more wisely. Yes, it may not be easy, yes, it may take someone brave enough to say **NO** this is not the best way forward. Perhaps someone needs to think outside of the box and be a realist. Perhaps double funding should stop, that will save money, but should that money not go directly to fund a person's choices without them needing to move out of their home? Why can't personalisation be for everyone and to include those in residential care? That way, nothing is lost, personal gain can be achieved and my friends can have a degree of control over their lives.

I'm very lucky not to have a learning disability. I can almost choose what I do on a daily basis as can you. I can voice my thoughts and feelings; I'm in control as are you. So please think before you make a choice. The results will have an effect on a person's life, one that is always a struggle.

Thank you for your time.

Regards

Clare

Fortunate are we that we are not the less fortunate.

Consultation Principles 2016

- A. Consultations should be clear and concise**
Use plain English and avoid acronyms. Be clear what questions you are asking and limit the number of questions to those that are necessary. Make them easy to understand and easy to answer. Avoid lengthy documents when possible and consider merging those on related topics.
- B. Consultations should have a purpose**
Do not consult for the sake of it. Ask departmental lawyers whether you have a legal duty to consult. Take consultation responses into account when taking policy forward. Consult about policies or implementation plans when the development of the policies or plans is at a formative stage. Do not ask questions about issues on which you already have a final view.
- C. Consultations should be informative**
Give enough information to ensure that those consulted understand the issues and can give informed responses. Include validated assessments of the costs and benefits of the options being considered when possible; this might be required where proposals have an impact on business or the voluntary sector.
- D. Consultations are only part of a process of engagement**
Consider whether informal iterative consultation is appropriate, using new digital tools and open, collaborative approaches. Consultation is not just about formal documents and responses. It is an on-going process.
- E. Consultations should last for a proportionate amount of time**
Judge the length of the consultation on the basis of legal advice and taking into account the nature and impact of the proposal. Consulting for too long will unnecessarily delay policy development. Consulting too quickly will not give enough time for consideration and will reduce the quality of responses.
- F. Consultations should be targeted**
Consider the full range of people, business and voluntary bodies affected by the policy, and whether representative groups exist. Consider targeting specific groups if appropriate. Ensure they are aware of the consultation and can access it. Consider how to tailor consultation to the needs and preferences of particular groups, such as older people, younger people or people with disabilities that may not respond to traditional consultation methods.
- G. Consultations should take account of the groups being consulted**
Consult stakeholders in a way that suits them. Charities may need more time to respond than businesses, for example. When the consultation spans all or part of a holiday period, consider how this may affect consultation and take appropriate mitigating action.
- H. Consultations should be agreed before publication**
Seek collective agreement before publishing a written consultation, particularly when consulting on new policy proposals. Consultations should be published on gov.uk.
- I. Consultation should facilitate scrutiny**

Publish any response on the same page on gov.uk as the original consultation, and ensure it is clear when the government has responded to the consultation. Explain the responses that have been received from consultees and how these have informed the policy. State how many responses have been received.

J. Government responses to consultations should be published in a timely fashion

Publish responses within 12 weeks of the consultation or provide an explanation why this is not possible. Where consultation concerns a statutory instrument publish responses before or at the same time as the instrument is laid, except in exceptional circumstances. Allow appropriate time between closing the consultation and implementing policy or legislation.

K. Consultation exercises should not generally be launched during local or national election periods.

If exceptional circumstances make a consultation absolutely essential (for example, for safeguarding public health), departments should seek advice from the Propriety and Ethics team in the Cabinet Office.

This document does not have legal force and is subject to statutory and other legal requirements.

*To all of you who cared for me
I write this to say
You Helped Me
Your tender voice,
Your soft gentle touch,
How you sat me in my chair, and such.*

*You put a blanket on my knee
When it was cold you thought of me.
You gave so much
I gave nothing in return
But without your help
My skin would burn.*

*I cannot talk
I cannot speak
Sometimes my world feels so bleak
I cannot walk I cannot run
Sometimes in my world I have no fun*

*I cannot taste I cannot drink
Sometimes I cannot even think
Not just to wish or wonder what it is like
But get out my chair and ride a bike
To shout, and cry, or just say NO
How it must feel I will never know.*

*To you my world may seem dull
It may cross your mind that yours is full
But just for a while imagine this,
then rethink your wish list*

*Just for a while, think of me
And think how my world looks, as I can't see
But I do know when someone cares,
It's when you touch me or do my hair.*

*Id thank you in person if I could
But Im now in a box, it's made of wood
But whilst I was here you cared for me
You spoke you giggled as if I was free*

*You spent your time doing your best
You helped me with my zipper vest
Id of died of thirst if it wasn't for you
And few to many are there like you*

*To those who locked me in my room
When I was wet or hungry full of gloom
When I was poorly feeling ill
Some of you didn't do the drill
You'd leave me there in my bed
So your shift was easy, that's what you said
Well go to hell and come back as me
See how you'd like it you heartless 3*

Joanne Twomey

From: Joanne Twomey
Sent: 11 October 2016 12:01
To: Joanne Twomey
Subject: Cabinet Meeting today

Joanne Twomey
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From: Sara Brennan **On Behalf Of** Mr. N. J. Rushton
Sent: 11 October 2016 11:56
To: Joanne Twomey
Subject: FW: Cabinet Meeting today

Sara Brennan
Secretarial Support Assistant
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From: Peter Warlow [<mailto:peter.warlow@glebehouseproject.org.uk>]
Sent: 11 October 2016 09:26
To: Mr. N. J. Rushton
Subject: Cabinet Meeting today

Good morning, I am writing to you regarding the meeting you are chairing today.

The agenda includes an item asking the Cabinet to rubber stamp the reduction of personal budgets for adults with learning disabilities which has been the subject of a consultation.

The outcome of the consultation was very clear but in the words of Jon Wilson in an email to me "You are correct that my recommendation to members in the cabinet report is to approve the proposed changes to the CLC services whilst acknowledging that the majority of respondents to the consultation opposed the proposals.

I feel that although providers, carers and service users have definitely been consulted-so ticking a box-virtually nothing has changed as a result. I would hope that the cabinet, before they pass this measure, at least properly challenge why the overwhelming outcome of the consultation has been ignored and insist that a fully inclusive review system is in place, which allows all stakeholders to be present before life changing decisions are made.

Thank you for reading this email.

Sincerely

Peter Warlow
Chief Executive
Glebe House

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Flexible services for people
with learning disabilities

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