

**The Lewis & Mary Haynes Trust: Objections to the proposed merger of the Grange and Haynes dementia day care centres and closure of the Haven day care centre.**

The Trust objects to the proposed merger of the Grange with the Haynes dementia day care centre are on the grounds of:

- Insufficient capacity at the Haynes centre
- Unsatisfactory travel for clients from east of borough
- Alternative provision unlikely to be adequate replacement of day care
- Personal Budgets unlikely to cover alternative provision
- Need to meet future demand for dementia day care
- Inconsistency with National Dementia Strategy & Haringey Dementia Commissioning Strategy

Insufficient capacity at the Haynes centre

1. The Haynes Centre was designed to accommodate 20 clients [REDACTED], PCT project manager instruction to architects at day centre design meeting, 5 May 2004) This is borne out by the provision of 20 places in the dining area and the furnishing of the main space.
2. The Consultation paper refers to 40 people currently accessing the Haynes Centre, and that is correct. However, some clients come two days and others for three, and because of illness or for other reasons, only about 18 come each day.
3. Impact of merging the Grange with the Haynes: We do not have the latest take-up figures but using January 2011 figures, the combined Grange (152 place days) and Haynes (181 place days – based on 15 users at that time) will be 333 place days, or 111% of the Haynes capacity. The present take-up at the Haynes has increased with the rise in users from 15 to 18, and as a result of the closure of the Woodside Centre. Furthermore, closure of the Haven will require dementia day care for up to 27 people (EIA for Haven closure, June 2015)
4. Transfer of service users from the Grange to the Haynes – reassessment of Grange users: The Consultation paper states that the closure of the Grange would require reassessment or review of the current users with a view to identifying satisfactory alternative provision to meet the assessed needs. Because all users of the Grange and the Haynes are clinically assessed as having severe dementia, it is unlikely that further assessment will find their assessed need satisfied by a lesser provision. In addition, since the reassessment or review will be conducted “with a view to identifying satisfactory alternative provision to meet the assessed needs” there is a risk here of needs assessment criteria being adjusted to reflect the limited number of places at the Haynes.
5. Reassessment of Haynes users: Although the Consultation paper makes no reference to reassessment of present users of the Haynes Centre, the Equality Impact Assessment states: “The Haynes service users would also be subject to a re-assessment of their care and support needs.” The same considerations set out above would apply.
6. While it is certainly true that the Haynes centre, with 281 sq metres net floor space, is larger than the Grange, nearly a quarter of that (62 sm) is used for kitchens, offices, toilets etc. A further one-third (87 sm) is made up of smaller rooms used for therapeutic activities (reminiscence, art, music, library) leaving 30% (78 sm) for dining and 20% (54 sm) for the sitting area.

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Insufficient capacity at the Haynes Centre (cont)

It is these two spaces which determine the capacity of the centre. It is not possible to expand the daily attendance at the Haynes centre while maintaining an acceptable level of care, even with extra staff. There is not sufficient space in the areas that matter.

Unsatisfactory travel for clients from east of borough

1. At both the Grange and the Haynes, most clients are picked up from their homes, using centre-based vehicles with the driver and escort drawn from the centre's staff. These clients arrive about 10.30 am and leave about 3.30 pm.
2. An important reason for opening the Haynes centre was to provide dementia day care in the west of the borough, so eliminating lengthy journeys which deterred potential beneficiaries living in the west from attending the Grange.

Closing the Grange and transferring its clients to the Haynes re-creates exactly the problem the Haynes was established to resolve.

Furthermore, the longer travel time will mean that users from the east of the borough will arrive later and spend less time at the centre, so reducing the benefit of attendance.

Alternative provision to meet need

The day care centres provide around five hours of physical, social, and emotional care and stimulation, including small group orientated therapeutic activities such as poetry and play reading, singing, games, exercise, reminiscence and craft work. The centres enable social interaction between users, which can have a therapeutic effect on their behaviour. The importance of social activities such as the dementia day care centres provide, cannot be exaggerated; they are essential to the care of people with dementia.

Use of Personal Budgets

Both the Consultation paper and the Equality Impact Assessment state: "Service users will be encouraged to use their personal budget to access any support required to meet their assessed need." It is very unlikely that any users of the Grange or Haynes will have a Personal Budget sufficient to pay for the specialised dementia care required to meet their needs or for the travel costs resulting from dispersed alternative care.

Future needs for dementia day care

The most recent data on dementia in Haringey is "Haringey's profile of dementia" published in Public Health Intelligence, May 2015 and presented at the September meeting of the Dementia Steering Group. The figures given are:

In 2013/14, there were 886 people in Haringey who had been diagnosed with dementia and an estimated 400 further cases undiagnosed, giving an approximate 1,290 people with dementia in the borough in 2013/14

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**Future needs for dementia day care (cont)**

These figures are roughly the same as those in Haringey's Older People's Mental Health and Dementia Commissioning Framework 2010-2015 (NHS Haringey/ Haringey Council, January 2011).

Two points to make about these figures:

- Dementia is an incurable and progressive disease that progresses ineluctably through the stages of mild, moderate and severe. The users of the Haynes and Grove have been clinically diagnosed with severe dementia.
- Only about 40% of people with dementia receive a formal diagnosis. Successful implementation of the Haringey Dementia Commissioning Framework and the Pathway being developed by the Dementia Steering Group will lead to an increase in dementia diagnoses and a corresponding increase in need for day care facilities. This is already evident from the waiting lists for the Haynes and Grange.

It is hard to imagine that Haringey Council or the Haringey Clinical Commissioning Group will ever be in a position to open new centres to replace either the Grange or the Haven day care centres. So, in view of the inevitable increase in need, both the proposal to merge the Grange with the Haynes and the proposal to close the Haven will deprive future Haringey residents with dementia of the care they need. Looking to the future, these proposals make no sense.

**Inconsistency with National Dementia Strategy & Haringey Dementia Commissioning Strategy**

Haringey Adult Services has adopted the goals of the National Dementia Strategy and in its Commissioning Strategy sets out the path to achieving them. These proposals run counter to these goals.

**Closure of the Haven day care centre**

The Haven Day Centre provides day services for adults over 65 years old, limited to 24 people per day, providing day opportunities to 53 Haringey residents. Over 50% of service users are aged 80 years or over. All users have a physical frailty or sensory impairment and/or require support with memory and cognition conditions, i.e. dementia, possibly up to 50%, some with dementia more advanced than moderate.

Closing the Haven day centre will inevitably place more pressure on the Haynes and Grange centres.

## **Hornsey Pensioners Action Group (HPAG)**

### **Response to Consultation by Haringey Council on Adult Social Care services**

**September 24<sup>th</sup> 2015**

The text in the consultation emphasises the importance of preventative care, keeping older people well.

We agree. This is a message that our group has campaigned for over a long period. Many things help keep people well; these include low cost health services such as physiotherapy & podiatry, eating well, local facilities for exercise classes, swimming and, not least, opportunities for older people to socialise.

The provision of community health services is currently provided by the NHS, and in past representations we have noted inordinately long waits.

In Haringey, hot meals to residents is provided by recommended firms, lower charge after means-testing.

Provision of facilities for exercise and centres at which older people can meet with one another, get advice and help is a local authority responsibility. In some they were able to get a hot meal. These work well at present and it appears that this consultation wants to close some of them.

**According to the stated aims, this is illogical to close them. Please keep open these centres where people get face to face attention with others.**

It also appears that the closure of Osborne Grove Nursing Home is proposed. Members of HPAG have had much involvement with the home. It cannot be verified that patients would fare better with '*re-enablement*' than by remaining in the home. In fact there are too few residential nursing homes to aid the transition from hospital to own home in Haringey. More Intermediate care was mentioned but no plans outlined.

#### **Do not close Osborne Grove Nursing Home.**

The recommended alternative schemes that would operate as Social Enterprises could not replace the facilities proposed to be withdrawn. It is possible that such enterprises would supplement the work of the centres and nursing homes; we note that Caring Connections was appreciated when supported for a short time by Haringey Age UK.

**However, it is not acceptable to out-source council responsibilities to Social Enterprises.**

In general, out-sourcing requires contract definition; this cannot cover everything and guarantee good quality of service. The path of responsibility would be broken and residents deprived of council care.

If the proposal to close the centres went ahead our members and pensioners across the borough would feel bereft.

## **Not covered in the consultation is Communications.**

For adequate delivery of Adult Social Care services a good system for communications is needed, and this is currently not the case. A resident calling on the telephone for a council service will be in for an exhausting process. There is an information spiel before any response, which is in the form of a series of choices. **The one number approach is difficult especially for older people.** When on the correct pathway there is a long wait and further information messages. Finally when through to the person dealing with the enquiry, this person is often untrained in telephone clarity, does his or her best but appears to be unsupported. There is no back up for email enquiry, and when the call ends how does one retrieve the decision made?

## **Assisted transport is needed.**

In relation to re-enablement the consultation makes no mention about transport for older people to those places where they can socialise. We don't want older people incarcerated in their own homes. Some of our members use Dial a Ride to get to our meetings, but find that they must book way ahead. This may indicate that more assistance of this sort is needed.

## **On-line consultations.**

Both on-line consultations included closures, so it appears that money needs to be saved to provide home-based care. Schemes are named but their remit not defined.

**The Consultation on proposal 1** was for *Increasing the council's capacity to provide re-enablement and intermediate care services.*

**The Consultation on proposal 2** was for *Increasing our capacity to provide suitable accommodation that promotes individual well being through expanding Supported Living Accommodation and Shared Lives schemes.*

If more information was supplied on those schemes we could comment. But we are totally against closure of existing centres and homes, and do not want council responsibilities delivered at 'arms length'.

[REDACTED]  
on behalf of Hornsey Pensioners Action Group  
[www.hornseypensionersactiongroup.org.uk](http://www.hornseypensionersactiongroup.org.uk)

[REDACTED]

This week on Fri 24th July the Council will be holding a consultation meeting with the carers on the future of day services for people with dementia, and on the future of the Haynes Day Care Centre. This is the only meeting offered to the carers at the Haynes. It would of course be best if we carers are informed of all the planned changes and proposals by all the providers before going to this important meeting.

Could I therefore please gently ask you if you could respond to my questions below relating to the Dementia Day Centre included in the BCF. Please provide as much explanation/ background/ info/ detail of the service as possible that's included in the BCF and how, if at all, it relates to the Haynes Day Care Centre.

Thanking you in advance,

Kind regards,

[REDACTED]

I'm the sole carer of my husband who attends the Haynes Day Care Centre for people with dementia, and also member of the Relatives Support Group there. I recently joined the Carers Reference Group set up by the Haringey Healthwatch, and as its representative attended the Dementia Steering Group last Wednesday - we were in the same room, but unfortunately I had to leave after the meeting promptly to collect my husband from his day centre much after their usual time.

I wanted to talk to you last Wed but that was not possible. Could I please seek some information from you re: the BCF. I refer to the BCF Community Event on Thursday 4<sup>th</sup> June 2015, and the presentation that you circulated the following day. I refer specifically to page 23 of the presentation "BCF Scheme & Service Overview" which summarises components of the BCF in a table format under 4 headings with indicative resources for 2015/16. Under Scheme 1: Admission Avoidance, a number of services are listed and £13.5m resources for 2015/16 is shown.

The services listed include Dementia Day Centre, as carers we would strongly agree that good dementia day care centres keep people with dementia healthy longer in the community, reduce their isolation, enhance quality of their lives, delays the need for residential care and reduces the need for hospital admissions. As carers we think that care at home does not provide such benefits and may in fact lead to isolation, lack of adequate support and default use of A&E services; carers' health and wellbeing are also effected with double impact on NHS.

Could I please ask you to give further information and explanation for the inclusion of the Dementia Day Centre on the BCF Overview table: does it refer to existing services, does it refer to such services needing to be provided and/or developed to help deliver BCF objectives, has there been any assessment of the level of need, does it reflect the major changes to dementia day care services following the recent decisions of the Council, does it take into account the increasing numbers of people with dementia, and does it indicate some BCF funding may be available to provide dementia day centre services, etc.

Thanking you in advance,

Kind regards,

[REDACTED]

I refer to Beverley Tarka's letter dated 3 July advising carers and clients of the Haynes and Grange day centres of meetings to be held later this month and in August regarding the proposed changes to day centre services.

I should like to know whether the meeting for carers (24 July at the Haynes) will be minuted or otherwise recorded for the benefit of those who are unable to attend. Since it is described as a "focus group session" I would not expect formal minutes of the discussions. However, it is important that *everyone* is properly informed of the "to help explain what the proposals will mean for you" aspect.

I should like more information about the "advocacy experts" who will be present at the meetings, in particular their professional affiliations. Sight of their brief would also be helpful.

I also require an assurance that as many of the day centre staff as possible will be present during the meetings with clients. Hayes and Grange staff are, from the viewpoint of our loved ones, familiar and trusted individuals. These meetings may be confusing and distressing for clients and minimising such distress must be a priority.

[REDACTED]  
Co-ordinator, Haynes & Grange Relatives Support Group

Cllr Kober et al.

I am writing to you to request your support in expediting the reasonable adjustment request below. HWF and the borough's DPO were not informed or invited to contribute to the consultation on Adult Social Care. Over a week ago I requested the papers and heard nothing until yesterday. I am still yet to receive any paperwork.

I have asked to receive the documents forthwith along with an extension to the deadline to enable LBH to consult with the people effected by these proposed changes and so you are not in breach of your statutory obligation and/or subject to legal challenge.

I look forward to hearing back from you shortly with a new deadline date,

[REDACTED]  
Representation Worker  
[REDACTED]

**Post:** Haringey Women's Forum,  
18a Edison Road,  
Haringey.  
N8 8AE.

**Online:** Haringey's Disabled People's Organisation, Enabling Haringey, has a [webpage](#)  
**Reasonable Adjustment:** I need information in plain English. Please use [this guidance](#)

**Donate:** You can help us raise funds through our [website](#), via [ebay](#) or by texting 70070 and quoting HWFA11. Don't forget to say 'yes' to gift aid.



Think before you print

Beverley,

Many thanks for your email.

I look forward to receiving the documents so we can consider your proposals for changes to Adult Social Care and so we are able to submit into the consultation.

**Given that I am yet to receive any documents to consider and it is less than a week from your original deadline, please confirm your new deadline in light of our reasonable adjustment request – will it be 90 days from the date that we receive the consultation documents?**

As I mentioned in my original approach over a week ago, LBH has an obligation to consult and engage people, particularly along the lines of protected characteristics (EA 2010).

HWF wishes to make sure that LBH is not in breach of its statutory obligations. Given the **delay in your response, might I suggest that you also email the accessible paperwork to [REDACTED] and [REDACTED] to enable us to disseminate it to our Board and service user groups.**

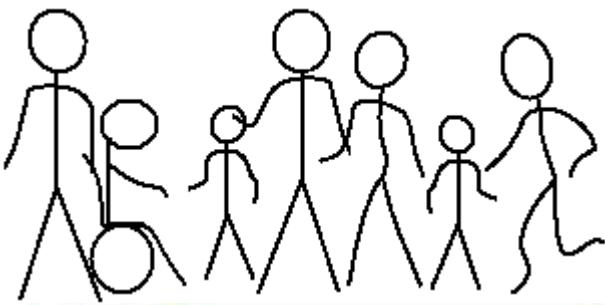
**I look forward to receiving the papers and new date shortly and working more closely with LBH in the future.**

[REDACTED]  
Disability Representation Worker

**Post:** Haringey Women's Forum,  
18a Edison Road,  
Haringey.  
N8 8AE.

**Online:** Haringey's Disabled People's Organisation, Enabling Haringey, has a [webpage](#)  
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 Think before you print

Nick,

I am getting in touch directly as I have just stumbled across the Adult Social Care consultation and need to understand what has happened around LBHs engagement, and get accessible documents speedily so that you aren't in breach of your statutory responsibilities.

Please **send me all the papers for this (these consultations) as a hard copy in plain English as a reasonable adjustment** ASAP. Address at the end of the email.

Please also **provide a new/alternative date for the end of this consultation, to enable the 90 day consultation period that LBH is committed to, to enable engagement of disabled people and women in Haringey.**

Please also clarify:

- 1) **How the EqIA were completed and which organisations** were approached to contribute the EqIA
- 2) How the consultation was **publicised; method and dates** (given that LBH has been informed numerous times that over half of disabled people in Haringey do not use the internet and therefore **relying on the internet to consult is, in and of itself, discriminatory**)
- 3) **Which VCS were approached** to respond to the consultation and **which equalities streams you considered them to be representing.**

As you know Haringey Women's Forum is the borough's women's organisation and the home of the borough's DPO so that fact that we were not informed about this consultation (given our reach and experience with women, disabled people including MHSU, BMER communities and LGBT, with particular experience around multiple marginalisation) **makes us somewhat concerned that LBH has not met its obligations around equalities or its commitments to consult.**

It is, of course, disappointing to discover a significant consultation that effects the vulnerable people you represent and work with by pure chance (via a online petition!) nearly three months in. HWF and the boroughs DPO are very keen to work with LBH to make the most of our limited capacities to ensure the most vulnerable are not disproportionately effected by austerity measures; in order to do so, however, we ask LBH to meet its statutory obligations and engage the VCS in a timely and appropriate manner.

I look forward to receiving the papers and new date shortly and working more closely with LBH in the future.

[REDACTED]  
Disability Representation Worker  
Monday, Wednesday and Friday

[REDACTED]  
**Post:** Haringey Women's Forum,  
18a Edison Road,  
Haringey.  
N8 8AE.

**Online:** Haringey's Disabled People's Organisation, Enabling Haringey, has a [webpage](#)  
**Reasonable Adjustment:** I need information in plain English. Please use [this guidance](#)

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[REDACTED] 27<sup>th</sup> July 2015 .

Dear [REDACTED]

can you please keep the  
centre open. I hope you  
can please keep the centre  
open and pay all the staff  
some more money to keep  
the centre open. Even the  
Hazen and Readwoy also and Always  
and Birchbeck road is closing. there  
is only one centre being left open  
and that is Ermine road. it is not  
fair for all the service users and  
Elderly .

I have received an invitation to a focus group at Osborne Grove Nursing Home on Wednesday 22nd July to discuss changes proposed for day services in Haringey.

As my sister is a long-term resident at Osborne Grove, I wonder whether there is any point in me attending as my sister is not in receipt of day services.

I would be grateful if you could clarify. I am eager to discuss what is happening with Osborne Grove, but I live on the South Coast near Portsmouth and do not want to come such a long way to a meeting if it is not relevant to my sister's future.

Many thanks

[REDACTED]

# **Haringey Adult Social Care Consultation: Proposal 3 Increasing the availability and flexibility of day opportunities within the borough meeting the individual needs of residents**

## **The Roundway day service for adults with autism and complex needs – a report on the impact of closure**

### **Executive Summary**

The Roundway is an autism-specific day service in the London borough of Haringey. It is run by the council and provides autism-specific support to people with autism, learning disabilities and complex needs to take part in various activities, learn new skills, and to meet new people to develop their social skills. It is known locally as the ‘Autistic Spectrum Service’, and provides day activities, both in the Roundway building and out in the local community.

The Roundway currently supports 27 adults with autism, learning disabilities and complex needs. There are 28 members of staff supporting the 27 service users.

Haringey Council have put forward a proposal to close down the Roundway service and provide day services using a new model of social care where activities are no longer delivered from a physical building but are delivered mainly ‘in the wider community’. <sup>1</sup>

In May 2015, a survey looking at the experiences of those using the Roundway service was sent out to all parents/carers of service users and, where service users had no close family, the residential homes in which they live. The survey gathered details of people’s needs and of their experiences of the support received from the Roundway day service. We received 21 completed surveys, from the 27 sent out.

The following are the key findings from the survey responses:

- Roundway staff were rated highly by all parents/carers in terms of support provided and expertise in autism and challenging behaviours/ complex needs.
- All service users had accessed new activities in the community due to the structured support from the Roundway service, many for the first time.
- The Roundway service has enabled individuals to build positive relationships and lasting friendships.
- The Roundway service provides essential respite for parents/carers – often the time their adult children spend at the Roundway is the only time parents have a break from their caring duties.
- Parents/carers overwhelmingly feel that the friendships and relationships their adult children have built with the support of Roundway staff would be lost if the service closed down and there were no consistent ‘base’ for their adult children to meet and build friendships and relationships.

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<sup>1</sup> Consultation – Corporate plan priority 2 empowering all adults to live healthy, long and fulfilling lives. Consultation on proposal 3: Increase the flexibility and availability of day services within the borough p.5

Detailed below are the key findings from the survey, including direct quotes from parents/carers and residential staff. All names have been changed to maintain anonymity.

## **Staff expertise and the importance of consistency**

"Roundway support gives daughter stability during the day, enables activities in safety with staff who are experienced and know her, and some sort of normal life for me."

**20 out of 21 respondents said that Roundway staff understood the needs of their children**

**17 out of 21 respondents gave staff the highest rating of having an 'excellent understanding' of their child's disability**

All parents responding to the survey highlighted the skills, knowledge and expertise of the staff supporting their children at the Roundway. We asked managers at the Roundway about the levels of training in autism that staff receive and were told that all staff have been trained in Autism Spectrum Disorders levels 1 and 2 SPELL (Structure, Positive, Empathy, Low arousal, Links framework). The Roundway management team have completed SPELL 4 which focusses on behavioural interventions, diagnosis and assessments. All staff have completed additional breakaway training to understand techniques to breakaway if a client is challenging towards them and to look at conflict resolutions.

Roundway staff receive regular supervision by trained members of management in Leadership and Management 4-5. The Learning Disabilities team provide Speech and Language Therapy and Occupational Therapy at Roundway for the service users. Parents and carers of service users also have the opportunity to link in with a physiologist who works alongside Roundway staff in the service in order to provide a holistic approach to care.

All service users are assessed by staff with autism experience and training to provide them with a person-centred programme of activity with identified goals and outcomes. This programme is reviewed every 16 weeks by the programme coordinator (keyworker), a member of management and the service user themselves.

The Department of Health review 'Transforming Care', was published in response to the abuse of people with learning disabilities and autism uncovered at Winterbourne View, and states that:

'It is crucial that staff who work with people with challenging behaviour are properly trained in essential skills...Better skills and training are an important part of raising standards overall and we expect providers to ensure the people they employ are properly trained.'<sup>2</sup>

The Roundway staff are clearly fulfilling best practice models for working with adults with challenging behaviour, and at present Haringey Council are meeting their obligations under the 'Transforming Care' programme.

As Haringey Council have not put forward any clear proposals for how this complex group of service users will be safely supported to access day opportunities in the absence of the Roundway, they will be putting an already vulnerable group of adults at further risk by closing a day centre which currently meets the needs of

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<sup>2</sup> Transforming Care: a national response to Winterbourne View Hospital p.39

very complex individuals. Haringey have stated that each service user will be ‘reassessed’ and if they still have needs that must be met, they will be given a ‘personal budget’. In this situation, it is unclear what other autism-specific services or care staff would be available in the local area for parents/carers to buy in with their ‘personal budget’. People with autism need to be supported by expert, well-trained, consistent staff – as they currently are at the Roundway.

This high quality of staff support, knowledge and expertise was consistently reflected in the survey responses. Our survey asked: ‘do you feel Roundway staff understand your child’s needs and difficulties?’ Of the 21 people who answered this question, 20 of them answered ‘yes’ and one said they didn’t know. Seventeen respondents then went on to rate the level of staff understanding of their child’s disability and individual needs as ‘excellent’.

The manager of a residential home where one service user lives commented:

*Staff have worked with three service users for years – knowledgeable, professional, friendly. Provides safe/enjoyable outlet of services.*

## Complex needs and challenging behaviour

"George will be lost and very upset not to come and his head banging and slapping, hitting himself, I think will get worse. This is George's life, he loves the Roundway and where would he go, and I can't have two boys at home both with having no where to go, that would not be fair."

**20 out of 21 respondents said their adult children attending the Roundway have 'challenging behaviour'**

**19 out of 21 respondents said Roundway staff were experienced at dealing with their child's 'challenging behaviour'**

**12 out of 21 respondents said that their child's 'challenging behaviour' had decreased since attending the Roundway**

The Roundway provides support for people with very complex needs. This was confirmed by 20 respondents who agreed that their adult child has challenging behaviour. We went on to ask about the frequency of this challenging behaviour: nine people said that this behaviour occurred 'most days', seven said it occurred 'occasionally' and three people reported it as happening 'every day'. This is a significant proportion of Roundway clients who exhibit challenging behaviour on an almost daily basis and who are only able to access community activities due to having a team of autism-trained, expert staff around them, operating from a known and safe building.

The recently updated 'Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy' sets out what local bodies should be doing to support people with complex needs and whose behaviour may challenge. The statutory guidance states that 'behaviour others may find challenging lessens with the right support and individuals benefit from personalised care and living in the community... Services that can meet the needs of people with complex needs are essential to minimising the use of secure health settings.'<sup>3</sup>

Significantly, 12 people reported that the frequency of their child's challenging behaviour had decreased since attending the Roundway service, highlighting the effectiveness of support strategies employed by staff at the Roundway service. This provides evidence that through the Roundway service, Haringey Council are currently meeting their responsibilities in providing the right support for individuals with some of the most complex needs and are also fulfilling their statutory duties under the Autism Act 2009. The statutory guidance published alongside the updated national Autism Strategy contains a chapter on 'Supporting people with complex needs, whose behaviour may challenge or who may lack capacity'. This chapter highlights that good practice in supporting people with autism, learning disabilities and challenging behaviour emphasises:

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<sup>3</sup> Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy p.46

- The responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers
- That commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour; and
- That services/support should be provided locally where possible<sup>4</sup>

The Roundway service meets all of the above requirements.

The causes of challenging behaviour can be extremely difficult to understand, especially in people who have a diagnosis of autism and have only limited communication, as is the case for many of the Roundway service users. The fact that their challenging behaviour is well managed and has decreased in a significant number of service users is testament to the effectiveness of the staff, the strategies, and the service as a whole. Closing the Roundway service brings higher risks of challenging behaviour increasing and may put service users, family members and care staff at greater risk of injury or harm.

The ‘Transforming Care’ report also stresses the importance of local authorities providing a range of appropriate services for people with challenging behaviour, learning disabilities and/or complex needs within peoples’ local area. The report reiterates the responsibility of local commissioners to commission local services which provide expert staff and safe environments for people with these very complex needs, and that they must work with local people using these services when looking at this type of provision in the community:

‘Social care and health commissioners will be accountable to local populations and will be expected to demonstrate that they have involved users of care and their families in planning and commissioning appropriate local services to meet the needs of people with challenging behaviour. Families and self-advocates have an important role to play in challenging local agencies to ensure that people have local services and the optimum model of care.’<sup>5</sup>

Haringey documents state that they want all individuals to lead fulfilling lives where choice and control allow them to access the community just as anyone else does. They state in their latest consultation document:

‘All people with learning disabilities have the right to lead their lives like any others, with the same opportunities and responsibilities. The shift from buildings based care to community led support will enable all adults to make informed choices to enable the best outcome for them.’<sup>6</sup>

It is concerning that there is no evidence given to show how a move away from buildings based community provision will lead to people with learning disabilities and autism making more informed choices and having access to more appropriate care – particularly if the staff who know and understand these service users are no longer there to support them to make choices.

The nature of autism, learning disabilities and conditions where there are complex needs and significant challenging behaviours present, dictate that in order for choice and accessibility to be exercised, certain other factors and structured support networks have to be in place to enable people to do this meaningfully. Such factors include trained staff in autism and complex needs, a predictable environment where individuals feel calm and safe, and specialist communication strategies.

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<sup>4</sup> Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy p49-50

<sup>5</sup> Transforming Care: a national response to Winterbourne View Hospital p.28

<sup>6</sup> Consultation – Corporate plan priority 2 empowering all adults to live healthy, long and fulfilling lives. Consultation on proposal 3: Increase the flexibility and availability of day services within the borough

## **Accessing the community, socialising and maintaining relationships**

**"My daughter has attended services for over 20 years, all original users are good friends, stressed if don't see each other (eg. Away because ill)."**

**All 21 respondents said their adult children have difficulty going to new or unknown places**

**20 out of 21 respondents said their child had been supported by the Roundway staff to go to new places or try new activities**

**5 out of 21 respondents said their child would have no contact with people outside their immediate family if they stopped going to the Roundway**

**10 out of 21 respondents said their child would have very little contact with people outside their immediate family if they stopped going to the Roundway**

**5 out of 21 respondents said their child would have occasional contact with people outside their immediate family if they stopped going to the Roundway**

Our survey asked respondents if their child has difficulty going to new or unknown places, to which all 21 answered 'yes'. We then asked how frequently their children have difficulty going to new places to which 11 responded that their children 'often' have difficulty with this and a further nine people said their children 'sometimes' have difficulty going to new or unknown places. One person said that their child only 'rarely' experiences problems with this.

Despite high levels of difficulty with accessing the community, all respondents agreed that the Roundway staff have enabled and successfully supported their children to go to new places, 13 of whom said their adult children now go out to new places 'regularly'.

Due to the nature of autism, building relationships and friendships and interacting with people outside immediate family, can be immensely difficult. People with autism are particularly vulnerable to social isolation. In 2012 the NAS conducted research which found that 66% of adults with autism describe their main friends as their family or carer. Friendship and social interactions become even more of a struggle for those who also have a learning disability, with one third of this group reporting that they have no friends at all.<sup>7</sup>

Of those who responded to our survey, 17 service users have a diagnosis of Autism and Learning Disability, putting the majority of these Roundway attendees into the category of people who potentially have significantly lower contact with anyone outside their immediate family or carers. Bearing in mind the

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<sup>7</sup> (Bancroft et al (2012). The way we are: autism in 2012. London: The National Autistic Society.)

difficulties this group of people usually has with social interaction and friendships, 20 people reported that the Roundway service had helped their child to meet new people and build positive relationships with people outside their immediate family.

We also asked if their adult children had positive relationships or social contact with other people before attending the Roundway service, to which 10 said 'no' and eight said 'yes'. The following comment was made by a mother in relation to her daughter's progress in this area:

*'Since my daughter went to Roundway she has made friends, knows them by name'.*

What is concerning however, is that 10 respondents said that their adult children would have only 'very little' contact with people outside their immediate family/carer if they no longer attended the Roundway service. Five respondents said their children would have 'no' social contact with others if they no longer attended the Roundway and five said that their child would only have 'occasional' contact with people outside their immediate family/ carers if they were no longer able to attend the Roundway service. One person did not answer this question.

The Roundway service currently fulfils the statutory duty on local authorities, NHS bodies and NHS Foundation Trusts to:

'consider how to promote the article 8 right to family life for people with autism, including opportunities for friendships and family contact, to a life in the community where possible, and the opportunity to develop and maintain relationships.'<sup>8</sup>

Haringey Council will be at risk of no longer fulfilling this duty if they decide to proceed with the closure of the Roundway service.

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<sup>8</sup> Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy p.48

## **End of buildings based provision and the impact of closure**

"Roundway provides safe, reliable service that son looks forward to attending every day. Collected most mornings by escort who he's worked with for years. Routine and stability crucial with additional mental health needs / wellbeing. Having structured day leaves him happy/ fulfilled – all I could want."

**20 out of 21 respondents said that it would affect their child 'very badly' if they could no longer attend the Roundway service**

Without clear alternative proposals from Haringey Council detailing exactly how Roundway clients will continue to access day opportunities, it is impossible to know how people with such complex needs will be served by the new model of social care. The only details given so far about how day services will be delivered once the Roundway service has shut down include a statement that: 'Service users will be encouraged to use Personal Budgets to access any support required to meet assessed need.'<sup>9</sup>

Even if service users are reassessed and given personal budgets to access support, to our knowledge, there is no other appropriate, local, autism-specific service for individuals with this level of complex needs to spend their personal budgets on. Currently, the Roundway fulfils the specification for appropriate day services for people with complex and challenging needs who have an autism spectrum disorder. Closing the Roundway service would take away the only existing local service appropriate to this group of adults with autism and very complex needs, and Haringey Council will be at serious risk of failing to meet their duty to provide local services for this group under the Care Act, 2014.

Our survey asked parents, carers and residential staff 'How do you think it would affect your child if they could no longer go to the Roundway service?' Twenty out of 21 respondents answered that this would affect their child 'very badly'. We also provided space for respondents to add any comments about the impact on their child of the Roundway service shutting down. One residential staff manager stated:

*"Stan needs time out of home and away from people he lives with, supported by staff who understand his needs. Also needs activities which enable him to develop existing skills to socialise/ explore the community/ exercise / mental stimulation – Roundway delivers this."*

A family member of another service user said:

*"Service understands individual needs, encouraging him to get involved in activities. Doesn't like change and takes long time to get used to new people and be mentally stable – closing would be absolutely devastating, cause him depression and anxiety."*

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<sup>9</sup> Consultation – Corporate plan priority 2 empowering all adults to live healthy, long and fulfilling lives. Consultation on proposal 3: Increase the flexibility and availability of day services within the borough p. 6.

Original proposals from Haringey Council state that: ‘As part of our transformation of social care we will end the use of buildings based care for all customers living in residential care or supported living settings.’<sup>10</sup>

This seems to indicate that those in residential care currently accessing the Roundway day service will be the first to have their activities and level of support cut. The expectation is that the residential or supported living service where they reside will now provide day activities. It is unclear how far Haringey Council have informed residential and supported living institutions that they will now be required to provide day opportunities or the extent to which the Council have liaised with residential providers about whether they have appropriate levels of staffing and funding to enable them to provide day opportunities. Haringey Council have stated that: ‘we will work with residential and supported living providers so that adults, in particular, those with 24 hours residential support, will be supported to directly access alternative services in the community.’<sup>11</sup>

It remains unclear whether residential placements have the budget and/or staff to support their clients out in the community or what these ‘alternative services in the community’ are. Supporting people within residential settings is quite different from supporting people out in the community and staff will require different skill-sets to support people in this way. They will need autism training and expertise and will need experience at supporting people with complex needs and challenging behaviours to carry out activities in the community. Many people who use the Roundway will need more than one support worker to take them out into the community safely. Ten of the 21 respondents to our survey said that their adult child needs more than one-to-one support.

Currently, the Roundway service and building is a place that provides a safe and supportive space for people with autism and complex needs to spend time with their peers and to build and maintain friendships. The loss of the building and of the dedicated team of staff who run the Roundway, will undoubtedly lead to a loss of friendships, relationships, and contact with others that these clients currently cannot access anywhere else. A key difficulty for people with autism and complex needs is communicating and socialising with others. It takes extremely knowledgeable and expert support staff to enable people with autism and complex needs to build relationships. This is a skillset that comes from many years of working with people with autism. It can take months and sometimes years, for people to understand and recognise how an individual with autism communicates their feelings, wishes and likes and dislikes. In the same way, it can take many months or years of intensive work with one individual with autism to understand the causes and triggers for their challenging behaviour.

Many of the staff at the Roundway have worked with the same service users for years – staff have moved from different day services along with their clients, and even with a trusted member of staff supporting them through these previous transitions, many of the service users have experienced extreme distress at changes to services over the years. Parents told us that these transition periods have been marked by increased challenging behaviours and self-harming.

Change poses huge difficulties for people with autism, learning disabilities and complex needs. Trusted and experienced staff have previously been there to ease clients’ anxiety and to put in place strategies to help

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<sup>10</sup> Corporate Priority 2 – Savings, New pathways for people with learning disabilities – day opportunities, Haringey Council papers.

<sup>11</sup> Consultation – Corporate plan priority 2 empowering all adults to live healthy, long and fulfilling lives. Consultation on proposal 3: Increase the flexibility and availability of day services within the borough p.6

them to adapt to new environments and people. Parents and staff have expressed extreme concern about the impact that the closure of the Roundway would have on service users. It will not just be the immediate loss of the building, the staff and their friends that will have a negative impact on service users, but it will be compounded by the fact that there is no safe alternative being proposed to replace the service. The consequences will also be felt by parents/carers and family members who, along with the service users, are often the most frequent recipients of ‘challenging behaviour’. Such a huge loss – of staff, friends, routine, and a trusted environment – is likely to lead to a rapid increase in challenging behaviours which, in turn, could lead to parents/carers and others’ safety being put at risk. Physical health will be negatively impacted by self-injurious behaviours and many parents have reported a rapid decline in their children’s mental health when they have faced major changes previously. All of this will impact on other services such as mental health and crisis teams, and will put service users in danger of being admitted to the very institutions which provisions like the Roundway, are designed to keep them out of.

## **Listening to parents/carers/ professionals feedback**

"My daughter moved from Central to the Roundway which I was informed was an autism specific service. My daughter enjoys attending the service and they encourage her to attend college although this has not happened yet she has the option to pursue this if she wants. It would be a terrible loss if the service were to close."

The message from parents and carers is clear: do not close the Roundway service. It is a highly valued and excellent service. Haringey Council have a duty to listen to the opinions and wishes of these parents/carers and to act on these wishes.

The statutory guidance published to support the National Autism Strategy states that local authorities have to: 'Using a variety of methods, listen carefully to the views, feelings and beliefs of people including those with autism and their carers'.<sup>12</sup>

During a consultation by Haringey Council earlier in 2015, service users, carers and parents overwhelmingly responded to say that the day services provided invaluable support and respite. Haringey Council nevertheless voted through proposals to shut the day centres, even though it was the closure of day services which garnered the most responses to the consultation. As stated by the statutory guidance, local authorities must listen and respond accordingly to the views and feelings of people with autism and their families and carers, and we urge Haringey Council to fulfil their statutory duties by listening to and acting on the feedback received from parents/carers, service users and professionals.

When Haringey Council submitted their Autism Strategy Self-Assessment form in March 2015, reporting on their progress on achieving the requirements of the Autism Act and Adult Autism Strategy, the adult social care department included an example of good practice to demonstrate how they were enabling people with autism to access good quality autism services. The example they included in their self-assessment came from a person with autism who attends the Roundway day service.

It is significant that in order to demonstrate how Haringey Council are meeting the requirements of the Autism Strategy, they themselves recognised and shared an example of a service user from the Roundway service. This individual is clearly receiving high quality, expert, appropriate care and support from a day service tailored specifically to the needs of people with autism, learning disabilities, challenging behaviour and complex needs. Haringey were rightly proud of this – using it as their sole example of good practice in their self-assessment submission.

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<sup>12</sup> Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy p.33

Below is the full case study which has been taken from Haringey Council's March 2015 self-assessment submission:

I am a 28 year old female with Autism and currently attend The Autistic Spectrum Service 5 days a week. I choose to be non verbal but like people to speak verbally to me and I will give you a written response. I can sign and understand Makaton but would rather you talk to me.

I used to go to Central Day service but with all the changes in September 2013 I moved to The Roundway.

When I found out I was going to have to move I was a bit unsure of what it would be like but staff were good at reassuring me and keeping me informed.

I was happy to know that all my friends and staff that I knew was coming with me.

I had my own social story with pictures of staff, the buildings and other service users. Staff went through this with me everyday. We went for weekly visits to The Roundway for tea and biscuits and tried some sessions there. It felt good to be part of the changes and to always know what was going on.

Since the move I now get to go out a lot more and have more choice of what I want to do. I always like to know what I am doing. Staff ask me where I want to go and what I want to do, they listen to me and are very helpful. Even when I want to do something that is not always possible straight away staff explain why and when I will be able to so.

Having the same staff is important and makes me feel safe and happy to tell them what I want and how I feel.

I now have my own personal weekly programme which I really like as I know what I am doing and feel in control. I am now going out on trains, visiting places of interest to me, playing snooker, going to the gym and swimming, cycling, baking; sewing, candle making and next week will be starting Football and Boxing. I can now also use the I-pad by asking whenever I like which makes me understand things and allows me to look at interesting things of my choice.

I am very happy at The Roundway, I do a lot more of what I choose and help out with others too. If I didn't come to Roundway I wouldn't do anything.

## Conclusion

Our survey results provide concrete evidence of an excellent day service which is working well for adults in Haringey with autism and complex and challenging needs. This group of service users are some of the most vulnerable adults in the community who require good quality, consistent care, which they are currently receiving at the Roundway, and must continue to receive at the same level.

Haringey Council must acknowledge that the people who attend the Roundway have enduring, complex and lifelong disabilities which require ongoing high level support. The nature of their disabilities mean that they will require substantial, expert, specialist and consistent support throughout their lives in order to make choices, to build and maintain relationships, to go outside their home environment, and to access the types of community activities those without disabilities take for granted.

The negative impact of closing the Roundway on the lives of these individuals and their families will be considerable and numerous, and will take away the only meaningful relationships they have outside of their immediate family. The staff, their autism expertise, the safe and specially adapted environment of the Roundway building, and having a team of skilled care workers around the service users, are key to this group's success in achieving the outcomes as set out in their care and support plans.

All the parents who responded to our survey were strongly opposed to the closure of the Roundway service, and were extremely concerned about what the future would hold for them and their adult children if the service were closed. Parents made it clear that their children have been through many different services, and been supported in different ways over the years but that the Roundway service was by far the most appropriate and successful support their children had ever received.

The Roundway service mirrors day services run by the NAS, where individuals have personalised activity plans, and activities are accessed from a known and safe building, staffed by a team of care workers trained in autism. Due to the nature of autism, a team around the individual is essential. No detailed alternative proposals have been put forward by Haringey Council which come anywhere near to providing the support and services which are needed by those who currently attend the Roundway. Moving service users to the Ermine Road day service is not an appropriate alternative. Plans to turn it into a social enterprise mean that the staffing and running of it could potentially look vastly different from its current form. There is no guarantee that staff will be trained or experienced in supporting individuals with autism and complex needs. It is a day service which will continue to serve an extremely wide range of disabilities and placing people with autism and challenging behaviour amongst many other service users poses significant safeguarding risks for both the individuals coming from the Roundway, and other service users accessing Ermine Road. Many parents whose adult children used to attend the Ermine Road day service told us that it was previously deemed as inappropriate and unsafe for autistic service users, making Haringey's plans to move current Roundway service users back to Ermine Road extremely worrying.

If proposals are taken forward to close the Roundway service, those individuals currently attending the service will undoubtedly experience huge anxiety and distress. We have been told that due to the uncertainty around the day centre's future, challenging and self-injurious behaviours have already increased in recent months.

Under the Care Act and the Autism Act, Haringey Council have a duty to provide appropriate and good quality day services for this group of vulnerable service users who have been assessed as having care and support needs that must be met. The NAS believes that in removing the Roundway day service, the Council would be seriously risking not meeting these statutory duties.

Haringey Council's current proposal to close down the Roundway service places an unacceptably high risk on the mental and physical health of these autistic adults, on their overall wellbeing, and on their ability to access their local community in a safe and appropriate way. The National Autistic Society strongly recommends that this excellent day service remains open.

### **Recommendations:**

- The evidence here clearly shows that the Roundway day service should not be shut down. It is a highly valued and effective service which delivers the outcomes of increased wellbeing, building relationships, accessing the community, and a reduction in challenging behaviours for a group of people with very complex needs for which specialist knowledge and skills are a necessity.
- In order to, most effectively, fulfil its statutory obligations under the Autism and Care Acts to provide local, good quality services for people with autism and complex needs, Haringey Council should keep the Roundway day service open.
- Parents of adults who attend the Roundway service do not want the service to close. Haringey proposals for day services must reflect and incorporate the views, wishes and priorities of people with autism, learning disabilities and complex needs and their parents, carers, family members, and professionals working closely to support them, and we urge the Council to take on board the strong views from parents to retain the Roundway service.

**September 2015**

**For more details please contact Anna Nicholson at [anna.nicholson@nas.org.uk](mailto:anna.nicholson@nas.org.uk)**

From: "██████████" >

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Date: Wednesday, 30 September 2015 02:58:15

Subject: Fwd: CHANGES TO HARINGEY'S ADULT SERVICES - EXECUTIVE SUMMARY

To: "Cllr Morton Peter" <Peter.Morton@haringey.gov.uk>

Cc: "Catherine West" <[catherine.west.mp@parliament.uk](mailto:catherine.west.mp@parliament.uk)>, "," <[Lynne@LynneFeatherstone.org](mailto:Lynne@LynneFeatherstone.org)>, "Cllr Bob Hare" <[reply@haringeylibdems.org](mailto:reply@haringeylibdems.org)>, [REDACTED] "Edwards Dionne" <[Dionne.Edwards@haringey.gov.uk](mailto:Dionne.Edwards@haringey.gov.uk)>, "Hunte Eugenie" <[Eugenie.Hunte@haringey.gov.uk](mailto:Eugenie.Hunte@haringey.gov.uk)>

Hello Peter

Perhaps you have not yet returned from holiday? But I am concerned that I have not yet had any acknowledgement or reply to my note to you dated 25 th September (copied below) especially since the consultative period regarding the Cabinet's proposals to change the delivery of services to Haringey's Adult Services ends tomorrow 30.09.2015.

My beloved husband [REDACTED] died

friend and mentor of so many, fell victim to the cruel, progressive and incurable Disease that is no respecter of persons - the vast majority of whom are cared for 24/7 365 days and nights (f.o.c.) by families and partners who - at considerable personal sacrifice - nevertheless take full responsibility for their stricken loved ones and devote themselves wholeheartedly to their care, well-being and quality of life. With all the "talk talk" of spreading resources more widely throughout the Borough there seems little or no real understanding of the NEEDS of both the patients now attending the HAYNES

- some 12 in number - or indeed of those throughout the Borough of Haringey who face CLOSURE or the privatisation/outsourcing of the services (already means tested) which in turn will NOT be neighbourhood based but amalgamated to serve the Borough as a whole, with all the attendant problems of transporting such disoriented, confused and very sick patients from all over the Borough to an unfamiliar neighbourhood staffed by persons (recruited by private enterprises run by for profit outsourced agencies) who take the jobs on offer because the wage they are paid just about covers their basic living costs. The present patients at the Haynes have formed PERSONALLY very close, trusting and significant relationships with the present staff and support workers all of whom without exception have a sense of commitment and vocation to their patients/clients/members. Anyone who has the slightest inkling of the nature of these devastating, incurable and progressive Diseases will know that those so condemned to live out the "life" that may remain for them here on earth ..for weeks, months, years or even decades ..that secure. FAMILIAR surroundings,amongst peers and support staff and with consistent, flexible but "steadfast" management true to its mission statement and agreed terms of reference, remit and job descriptions etc ARE MANDATORY.

My beloved husband (and I his registered full time carer) benefitted immeasurably from the few months that he attended the Centre (September 2014 - July 2015) The Centre provided not only social contact with [REDACTED] peers and REGULAR trusted support workers but also gave me his registered carer 24/7 365 days and nights a year a few hours to deal with the many other demands which I must meet,

I realise that protests of this kind are routinely ignored, brushed aside or stacked away with other unopened post, that little or no reference made to them as a whole ..("a huge response to which we cannot respond individually" let alone personally etc ... all part of the pantomime of make believe - a choreographed display of smoke and mirrors.. But I hope - perhaps in vain - that some small particle from this large chunk of impassioned personal protest may alight on the body politic and penetrate the thick skin of statistical data and the imperative to adhere to the principle of "cost effectiveness" (often illusory in actual practice). As one who is regarded as a self funder and taxpayer my comments are NOT motivated by self- interest and pecuniary advantage - I make these comments in the avowed belief that many of the proposals outlined in this latest consultative 'exercise' are ill conceived and potentially damaging - adding to the sense of confusion, fear, anxieties and discomfort to which these most vulnerable, frail and otherwise inarticulate of INDIVIDUAL PERSONS ARE ALREADY subject.

Peter, I am presently very poorly - probably because I have had little sleep during my beloved's last months of "life" wracked with the relentlessly cruel progression of symptoms that have no cure. And, as you will know, I shall myself be much preoccupied with all the responsibilities that now fall to me as widow. matriarch, executor, trustee, director, householder, taxpayer and Her Majesty's subject to discharge. I suffer from a progressive neurological condition that has become much more bothersome (with attendant severe pain) in the past year or so, most especially since June 2014 from which time I have suffered increasing pain, weakness and extreme fatigue. I cannot now contemplate further "action", meetings, discussions or even light gardening to tend our late daughter's last resting place etc whilst so unwell. Please Peter may I ask you to peruse this present message very thoroughly and to represent my views to the Cabinet as forcefully as your own terms of reference and remit allow.

I am now making arrangements for my [REDACTED] Memorial Service. This will take place at the end of October /very early November 2015 in the beautiful [REDACTED] and will be followed by a reception for [REDACTED] (and my) family, friends and colleagues from all over the world. You, Peter, are warmly invited to attend the ceremony and reception should you or others from the LA like to attend. Full details will be published in the national newspapers and on the Internet.

The very best of good wishes in all your deliberations. Please communicate by email/Royal Mail - I cannot always reach theb'phone in time to answer it!

[REDACTED]

[REDACTED]

Begin forwarded message:

**From:** [REDACTED]

**Date:** 25 September 2015 03:41:48 BST

**To:** Cllr Morton Peter <[Peter.Morton@haringey.gov.uk](mailto:Peter.Morton@haringey.gov.uk)>

**Cc:** "WEST , Catherine" <[catherine.west.mp@parliament.uk](mailto:catherine.west.mp@parliament.uk)>, Lynne Featherstone <[Lynne@LynneFeatherstone.org](mailto:Lynne@LynneFeatherstone.org)>, Cllr Bob Hare <[reply@haringeylibdems.org](mailto:reply@haringeylibdems.org)>b

**Subject:** CHANGES TO HARINGEY'S ADULT SERVICES - EXECUTIVE SUMMARY

**Reply-To:** [REDACTED]

Dear Peter

I do hope that you and your lady wife enjoyed your holiday in Kentucky. I expect yo have come back to a desk piled high, your inbox filled and overflowing. voicemail jammed and so forth. i believe you urged me to be in touch on your return to continue our discussions about some issues which concern me (and you/your Cabinet colleagues) greatly, I hoped we might meet up before the consultative period cam to an end on 30.09.2015.

I am deeply grieved to tell you that my husband died on [REDACTED] - we have been married for 60+ years, (SEE ATTACHMENT BELOW) My dearly beloved [REDACTED] attended the HAYNES CENTRE twice a week. We are "self funders" and are not entitled to any LA social or outsourced services. [REDACTED]

[REDACTED] - was diagnosed with Vascular dementia, Altzheimer's , prostate cancer four or five years ago. These cruel and relentless Diseases are no respecter of persons, devastating the lives and very *personae* of those they claim. Those who care for loved ones thus afflicted 24/ 7 for 365 days and nights, are often lauded but seldom supported in any meaningful or practical way, become cut off and alone, housebound - confined within the same 4 walls... close friends, neighbours, family members, colleagues and visitors tend to keep away, uncertain as to how handle the situation. [REDACTED] the linguist and world traveller suffered from dysphasia & dysphagia - a source of great frustration, and the many other depredations caused by these ruthless Diseases. Their insidious progressive nature can virtually entrap *the persona* within the outer physical shell.

THE CABINET MUST BE MADE FULLY AWARE OF THE CONSEQUENCES OF SPREADING THE RESOURCES AND CAPITAL INVESTMENT DONATED BY THE LATE HAYNES SISTERS THROUGHOUT THE BOROUGH OF HARINGEY - THUS DEPRIVING THE PRESENT INCUMBENTS OF THE HAYNES .. THE FAMILIAR SURROUNDINGS, THE SPECIAL FRIENDSHIPS, THE INTIMATE AND TRUST ENGENDERED BY THE VERY SPECIAL RELATIONSHIP THAT HAS BEEN BUILT UP OVER MONTHS/YEARS with the present dedicated staff .. *THIS 'CUT' is surely the unkindest cut of all - one that no transfusion of "outsourced" staff or private/charitable agency can possibly stem the haemorrhaging wounds to the ethos, mission statement and present management of the Haynes Centre, nor assuage the anguish, confusion, anxiety and fear of those to whom the Haynes, its management and staff represent the very centre of their lives, their identity as SOCIAL beings ..a haven of safety and warm understanding.* I KNOW THAT MY DEARLY LOVED HUSBAND WHO DIED [REDACTED]

[REDACTED] - *a very cruel and lingering death - preceded by years of suffering from Diseases that destroyed his very core - would not only miss his few hours a week in the company of his peers in familiar surroundings and with the devoted care and compassionate understanding of the present Management and staff - but that such a LOSS would annihilate the already rapidly diminishing quality of his life and even exacerbate the suffering that blighted his last remaining years.*

I attach a notice about the arrangements for [REDACTED] funeral. Should your many other commitments allow, you are of course warmly invited to be with [REDACTED] family, friends, carers and the many others who mourn his passing. See below.

I am somewhat concerned that you and I have not yet resumed our discussions, and 30th September looms! As you will understand I cannot just now turn my mind to other matters - the grief is unbearable, the loss immense. But I do feel very strongly about many of the "cost cutting" ploys being "considered" by the Cabinet and Civil Servants especially in the light of the fact that Haringey appears to be so profligate with taxpayers' money in so many other respects. What **services** does the local authority now provide directly - so many of these services are outsourced or commissioned by the Cabinet - meanwhile the authority spends vast sums of money "upgrading", "reforming", transforming... state of the art technology that often turns out to be not fit for purpose, the use of robots and automated systems that effectively BLOCK meaningful personal intercommunication between the residents/ taxpayers and the **Authority** - the world wide web is of course here to stay, bringing many many benefits to our globalised world; nonetheless the constant drone advising residents to 'GO ON LINE' means that the elderly, vulnerable, technologically illiterate and persons who cannot afford to invest in the latest technology are "shut out" - becoming ever more disadvantaged, disassociated from the main stream.

Surely it is to these PERSONS that the LA owe a duty of care - not those well connected, articulate, well heeled, well fed **apparatchiks ensconced comfortably in positions of power - becoming ever more remote and no longer directly answerable to those who "elected" them to represent them.** My beloved husband was born just after the [REDACTED].

After World War II he was destined never to see his family or homeland again. He was grievously wounded, condemned to death personally by Hitler and then by Stalin, narrowly escaping certain death on many occasions, tortured, forced labour, concentration camps.. he was the sole survivor of his generation - he was granted political asylum in Great Britain - but was looked upon as an Alien with no means of subsistence.. as a physicist and mathematician of some eminence he was considered overqualified for any job on offer at that time. King George VI provided him with a demob suit but he had but ten shillings in his pocket (50 pence) between him and destitution/starvation. Despite the challenges and vicissitudes he had to overcome, [REDACTED] was naturalised British in the late 1950s - and gradually extricated himself from the horrendous consequences of war, pestilence and disease - by his own efforts and initiative - contributing substantially to the British way of life, upholding its established values - not only paying his way but those of others, of the community as a whole as a taxpayer and

as Her Majesty's loyal subject. Nonetheless I am appalled by the remarks that have gratuitously been made to me in recent years by some of those in the caring professions to the effect that 'it is a waste of public resources to help/support those who are non-rehabilitable, incurably ill and doomed to die .. victims of unpredictable yet progressively

lethal Disease - the largest percentage of whom are cared for 24/7 365 days and nights a year by devoted family carers - at no cost to the State. I am frankly totally dismayed by many of the

proposals being 'considered' by the Cabinet - after several years of indecision and delay - that will undoubtedly do profound damage to those presently attending the Haynes Centre (including those who fund their own care and pay for the services provided by the Social Services/outs sourced agencies in Haringey) but also to the present management and staff of the HAYNES centre who have worked with a devotion and compassionate concern that surpasses all material considerations or personal self-interest.

I apologise for this rant ... but I feel a passionate concyyern about the increasing tendency to dehumanise PERSONS, subsuming them to the rule of robots - who are programmed by a faceless authority -

My kind personal regards - I appreciate your interest in my views - despite your suspicion that I am a dinosaur who cannot accept change/progress and is therefore doomed to extinction. I assure you that such suspicion is not warranted.. although I have observed that when the figure 80, 90 or even 70 is noted, the vast majority of professionals and even the general public, neither listen to nor respect the integrity of the long-lived oldie, indeed we are ignored, brushed aside - talked over our heads (the does she take sugar syndrome!) - treated as non-persons much like the robots who are programmed to react appropriately at the touch of a button, - or obliged to get into a one size fits all standardised 'uniform' and pushed onto a conveyor belt as just another anonymous package, to be processed, checked out and despatched....

[REDACTED]

PLEASE COMMUNICATE BY EMAIL. I AM SOMEWHAT DISABLED AND OFTEN CANNOT REACH THE PHONE IN TIME TO ANSWER IT!!

**From:** [REDACTED]  
**Sent:** 25 August 2015 05:10  
**To:** Cllr Morton Peter  
**Cc:** WEST , Catherine; Lynne Featherstone  
**Subject:** Re: CHANGES TO HARINGEY'S ADULT SERVICES - EXECUTIVE SUMMARY  
**Importance:** High

Dear Peter [if I may - my first name is [REDACTED] .. [REDACTED] - more formally (and rarely used nowadays) [REDACTED]

I thank you for your sensitive and understanding note 22.08.2015. I find many of the comments you make, personally very touching. Your fulsome apology for the delay in responding to my e-message 4.08.2015 is appreciated. Of course, I DO UNDERSTAND the glitches that occur (perhaps too often?!) in these days of 'instant communication' in a globalised world, having - like us all - experienced such!

My husband [REDACTED], - although very frail and weak - is to be discharged tomorrow [REDACTED] from the Whittington Hospital.

He will need round the clock 24/7 nursing care which I am arranging privately. It will probably take a few days for [REDACTED] to settle back home and for us to assess how best to meet the growing demands that the relentlessly progressive and incurable nature of these devastating diseases impose.

It is very thoughtful of you to give me such a wide range of the possible dates that you are able to visit. Very tentatively, may I suggest you pop by on Tuesday 1st September - after 5.30 p.m.? I much appreciate the opportunity to discuss these issues with you personally - as you rightly observe, these *tête-à-tête* are often more enlightening and informative than the 'feedback'

elicited 'at arm's length' by questionnaires, surveys or at public meetings. Whilst acknowledging the imperative to observe and respect each person's right to privacy and anonymity, I do believe the outspoken views of those who choose to disclose them openly are probably more "real and authentic" than those gleaned from the 'answers' to questionnaires circulated *en masse*

and specifically designed to facilitate subsequent statistical analysis and amorphous, generalised reports that meld the individual, disparate and diverse into a generalised survey punctuated by percentages, equations and logarithms, devoid of genuine, credible

and independent ideation.

I have also been in touch with our newly elected MP for Hornsey and Wood Green, Catherine West. I am convinced that the proposals presently under consideration are of crucial importance - not only to those described as this local authority's "service users" but also, nationally, to each and every resident, parliamentary constituent, taxpayer and democratically elected representative. I am attaching copies of a recent exchange of messages between Catherine and me. I am hoping very much that she may also become personally engaged in the ongoing consultative process, perhaps finding the time to "touch base" with you, Peter, if indeed she has not already done so. You will note the tone of her P.A's response to my correspondence on Catherine's behalf.

I look forward very much to your visit to our home - presently undergoing complete renovation, structural repairs and alteration as well as the refurbishment and renovation of our rather dilapidated and "not fit for purpose" domestic arrangements; we have lived here for more than half a century, the house itself having been built in 1901. At present our family home is enveloped in scaffolding, the front garden is a builders' yard (pro tem) and we are camping out in the drawing and dining rooms on the ground floor because the rest of the house has been gutted. Most of our furniture and personal effects are presently in storage .. but we can offer you a chair, some light refreshment and a very warm welcome.

In the meantime, I await my husband's return home; we owe a debt of gratitude to the paramedics, doctors, nurses and support staff at the Whittington - [REDACTED] would most certainly have died had he not been admitted to hospital urgently on Saturday 14th August. Now it seems that the sepsis and delirium have been brought under control - although of course he is very poorly and weak - BUT he will be back home again, in the familiar surroundings in which he has lived for more than half a century.

Should something "untoward" should happen to prevent your visit on Tuesday next, I shall try to telephone you on Bank Holiday Monday to forewarn you; alternatively, if convenient, you might

**telephone me before setting out to visit us on the Tuesday just to make sure that we are still here and awaiting your arrival!**

**Best of good wishes and thank you again for your empathy and understanding,**

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED] (voice mail most of the time so email is best!)

Dear Catherine

Thank you for asking your lieutenant [REDACTED] to acknowledge my electronic missive (NOT missile!) that finally sped its way to its intended target ..in the wee small hours of this morning! OF COURSE I appreciate the massive volume of messages that choke in-boxes to overflowing - much of it spam or unsolicited, irrelevant advertorial "guff" that not only wastes valuable space and time but also sometimes obliges the intended recipient to switch off entirely or to delegate the humanly impossible task of sorting, acknowledging, collating, keeping records, analysing, indexing and "inputting" the updated material onto computerised database to robots. I have myself been forced to divert the floods that inundate my mail box .. Today, for instance, there were no less than 579 automated, unsolicited and irrelevant electronic "communications" .. on a par with the extremely irritating "nuisance" and often dangerously intrusive telephone calls, text and voice mails. I have heard that MAYBE a more stringently enforced monitoring system may be introduced to dissuade these unwelcome interlopers from wantonly invading the privacy

and integrity of one's home - telephoning at all hours of the day and night - usually from outsourced call centres located abroad. Until I made stringent protest, some Banks and other large commercial organisations, introduced an automated tracking system to monitor any unusual or suspect transactions made on line. Crowds of computers were lined up in UNMANNED locations throughout the globalised world, their automated telescopic lenses pointed at the sky, searching for "fraudulent" transactions. But these robots are given minimal instructions based on electronically stored data, replete with numbers, passwords etc BUT zilch information or clue as to the true identity of the PERSON making the transaction. Thus a train of automated knee jerk robot-reactions are generated.. Unstoppable by Human hand or brain. This means that longstanding customers with impeccable records routinely receive an automated call from a robot which cannot even recognise or speak your name.. Monotonously intoning a gibberish announcement/statement that Fraud may have been committed ... And urgent action must be taken .. These calls are often made early in the morning .. Before 7 or 8 a.m. The Internet is limitless and cannot be managed or policed.. But my point is that ROBOTS are not our Masters but our servants. They can only operate as we instruct them to do. I believe that HUMAN input should retain CONTROL of the technology and TWEAK the glitches that inevitably occur when our robots go it alone,

**Catherine, I have already indicated in my last Long message that it is my avowed wish that both the LA and Parliament consider the implications of any proposed changes affecting the delivery of services which are funded by taxpayers. I hope to be in touch with Peter to arrange a Tête-à-tête ..but I hope very much that you and he will take the time and trouble to consider not only the best interests of local residents and tax payers but also those of your constituents ..who are not necessarily one and the same.**

**I must go .. To visit my husband who is still gravely ill.**

Best wishes [REDACTED]

Dear Ms Gromkyo

Thank you for your email. Catherine is very pleased to hear that you have now received a response from Cllr Peter Morton and hopes you find his visit useful. Please do let her know if there is anything further she can assist with in the future.

I am sorry that the 'auto reply' emails you received made you feel your email was being blocked. That is not the case. Catherine receives many hundreds of emails each week and sometimes it can take a few days to reply, so the 'auto acknowledgement' lets people know their message has got through and that they will receive a reply.

With best wishes to you and to your husband.

Kind regards

[REDACTED]  
[REDACTED]  
[REDACTED]  
|  
[REDACTED]  
[REDACTED]  
[REDACTED]

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**From:** [REDACTED]  
**Sent:** 23 August 2015 03:59  
**To:** WEST , Catherine  
**Cc:** Lynne Featherstone  
**Subject:** Fwd: Auto-reply: Thank you for your email to Catherine West MP

Dear Catherine

Good news! I have this evening received a reply from Peter Morton, You will see that he has accepted my invitation to visit me at home to discuss *inter alia* the ongoing consultative exercise about Haringey's suggested proposals *vis a vis* the provision and delivery of the LA's social services to the residents - (especially those over 65 and other vulnerable adults/youngsters with special needs) - who are also Tax payers - in the Borough. I understand that the Cabinet will not make an executive decision until December this year but that the closing date for comments and feedback is 1st October.

My husband [REDACTED] is presently in hospital (he collapsed, dangerously ill, 8 days ago and was rushed to the Whittington

for life saving treatment.) My husband and I have been married for [REDACTED]

I spend most of the day by his bedside so am not around to make/take telephone calls during normal working hours. I contacted you - our "new MP" (Highgate Ward) - because I was puzzled that I had not heard from Peter Morton whom I had invited (electronically)

to [REDACTED] on 4th August. I have just returned home from the hospital to find a message from Peter (21.07 hours).

I therefore retract the two further messages I had sent to you (see below) and apologise for hassling your office in this way. Belonging to the dinosaur generation I confess I occasionally feel that automated telephony - when robots take over from we humans - can undermine the INDIVIDUAL PERSONAL relationship and, too, uproot the old-fashioned ways of communicating with one another. "One size does not fit all" and I dislike "form letters/circulars" that are churned out automatically *en masse*. **Yes, of course I realise**, as a professional and business woman with years of experience, **that change is inevitable and NECESSARY - we must adapt or die** - post-millenium generations cannot understand **the aversion that those who were born and lived during the last century seem to have towards the technological, sociological, political, scientific and modus vivendi of the globalised world today!**

May I ask you kindly to forgive my (now superfluous) reminders that the robots [triggered automatically and electronically] intercepted and blocked so promptly and coldly yesterday and today?! Viz:

**SECOND request for a response (blocked)**

*I hope very much that my attempts to contact you - twice or three times now - are NOT blocked by the automated telephony that your constituency office has in place. I copy my original notes (sent electronically) below.*

**FIRST request for a response (blocked)**

*I do realise the pressures of a heavy workload but would MUCH appreciate an early response. I have asked Catherine for advice as to how to elicit a response to my e-message to Cllr Norton dated 4th August. I have written several times both to the Councillor and to the democratic secretariat but still no personal response. Are you able to remind him that I have been waiting to hear from him personally since early August .. And September will soon be here!*

Catherine - you may well wish to ignore this preamble - all sound and fury signifying nothing - hot air exhaled by an elderly person who happens to be the registered carer of a very dear one who has fallen prey to the ruthless, cruel depredations of vascular dementia coupled with Alzheimer's disease that insidiously destroys the very core of the person that was, leaving the remnants of a discarded physical shell

that lies rejected, often ignored or even excommunicated from the self-preoccupied busy busy (and sometimes ignorant or indifferent) folk in the everyday "REAL" world outside. Even today - in these days of enlightened 're-thinking' - those suffering from unpredictable, progressive and incurable disease become isolated and cut off from their peers and their former way of life, confined within the same four walls, day after day.. from which it seems there is no escape. Those dear ones **who have no family or friends voluntarily to take on** the TLC and full responsibility - (at considerable material and financial expense; frequently, too, at the cost of personal health and future security of those who WISH AND CHOOSE to take on the daunting challenge of this responsibility for an indeterminate period) - may well find themselves in alien surroundings, surrounded by strangers, faced with unfamiliar routines and often, sad to say, indifferent or even callously **Impersonal** care. Each of their familiar worlds shrink inexorably, their modest possessions, hobbies and former friends steadily diminish in the evening of their mortal lives - pitifully painful to observe and to witness. (I generalise and there of course many EXCEPTIONS where compassion, care and devotion safely cocoon each and every vulnerable, frail and needy **person**, shielding them from the vicious **TOLL** that the cruel vicissitudes, confusion and sense of overweening loss ruthlessly **EXTRACT**, but also opening the heavy doors that otherwise imprison and isolate, thus - once more - bringing light and the warmth of human companionship to those entrapped and seemingly insensate human beings.

You may consider my impassioned comments beyond the bounds of "appropriate" discussion between MP and constituent. In my long life [and throughout the breadth of my wide experience in many of the diverse fields that define the disparate boundaries of the countless areas of human history, endeavour and achievement], I have cared for many close family members; our younger daughter suffered for 20+ years from anorexia, tragically still an incurable and too often fatal illness, from the age of 12 until her death aged █; my late mother needed loving care for the last few years of her life as did my late father who lived with us in our family home for the last few months before he died; I was the principal carer of my late Aunt

who died at Christmas 2013, aged 100 years; I [REDACTED] I was the editor of a closed correspondence that formed a support network for and of those caring for those terminally ill with an eating disorder or who had been bereaved. I could itemise other of my voluntary interests over the years, but that is to overegg this one particular autobiographical aspect .. and is also irrelevant and boring!

Catherine, I believe I have already bombarded you with copies of my electronic messages to Cllr Morton. I hope very much that it will be possible to invite him over to our family home before August runs into September. The present consultative paper being widely circulated not only to the residents and taxpayers of the Borough of Haringey but to many other tangential but 'interested parties' **is of crucial significance and VITAL IMPORTANCE not only to Haringey's "service users" (hateful term) but - when Haringey makes its democratic executive decision in the dying days of 2015 and the new year 2016 - might well serve as the template for similar "democratically" derived social service (or any other LA service) policies henceforth in future.**

As long ago as the late 60s and 70s there was so much talk talk talk about Care in the Community [REDACTED]

[REDACTED] that were set up throughout the UK, most especially in deprived and disadvantaged large conurbations with a preponderance of high rise flats, often housing young single mothers with children, struggling desperately to survive and bring up their children alone.

There is still much talk talk talk about the IMPERATIVE that the NHS (a **national** and vast organisation, the largest employer of staff in the whole of Europe if not the world) and the Social Services provided by the Local Authority should LIAISE and co-operate or at the very least communicate between themselves, thus avoiding much duplication, waste and inefficiency. Both the NHS - a Goliath to the LA'S David - have established protocols, both employing a surfeit of administrators, pen pushers 'support' staff', statisticians, human resource and analysts who produce - for example - expensive, bespoke and professionally designed promotional, customer relation and information publications, many of which are distributed widely by Royal Mail from computerised records the data of which is seldom accurate, so that several copies of the same publication are duplicated/ triplicated/quadrupled to the same address, to each member of one family, married couples or partnerships or dead or gone away residents. Festoons of red tape choke the smooth running of both the NHS and Local Authorities. The obsession that every detail be recorded, computerised and REPORTED over and over means that staff working in the field spend more time writing reports than visiting/caring for patients/'CLIENTS' "IN THE FIELD". Both the NHS's and LA's propensity to turn to Agencies (at considerable cost) to fill staff vacancies with "temporary placement" or "supply" staff - all of whom are not salaried but who are paid much more pro rata than regular contracted staff, is indefensible. The agencies, outsourced service providers, and 'middle men" grow richer and richer,"earning" commission and other inducements at the taxpayers expense. Such "agency staff" are free to come and go as they please, and are usually more interested in the money they can earn than in the work they do or the patients they treat/serve. This practice undermines the employment of regular staff,, locums, temporary, part time and work experience staff, exchanges and so forth now predominate in many of the Primary Care, GP practices, Secondary and Tertiary Care '**tranches**' of the NHS and, too, the 'lower' echelons of Local Authority staff,

including the domiciliary Carers, employed by Agencies on pitiful wages whilst the Agencies themselves in turn charge extortionate fees to the 'CLIENTS' they purport to serve. Dedication, commitment are much less apparent. The concept of 'vocation', dedication or commitment seems to be subsumed to 'cost effectiveness', prioritising scarce resources, means testing, assessments of perceived needs. The cost of labour being high vast sums are spent on disposables, hospital equipment on loan that cannot be recycled once used, state of the art telephony and computer systems that turn out to be not fit for purpose, the proliferation of technological "gizmos" to most staff, some of whom have no training in their use do NOT improve the standards of service in themselves. Moreover, the huge MOUNTAIN of debt and punitive interest charges, plus contractual agreements that all service, repair and maintenance be outsourced rather than carried out by a regular, onsite workforce etc., the cost of stationery (mostly used by administrative staff), peripherals and miscellaneous promotional or 'for information' material, the cost of designing, running and maintaining websites - some of which are technologically inept and not remotely customer friendly, ditto the automated telephony - all add up to a huge bill which cannot be justified at the expense of VITAL FRONT LINE SERVICES. Similarly, I note the very favourable terms of engagement contractually agreed between the higher echelons of executive, administrative and managerial staff in both the NHS and in Local Authorities. I do not consider it ethically sound that the early retirement of Executive Officers be agreed and taken but who then decide to accept a consultancy in another Local Authority or NHS Department - all at the expense of the tax payer. I am tempted to use that old Orwellian platitude ... all pigs are equal, but some pigs are more equal than others.

Catherine I realise this long diatribe from an elderly constituent does NOT carry much weight but, in view of Peter Norton's thoughtful and insightful response to my earlier messages to him (**please refer to the attached copy**) it maybe that you and he might exchange your *personal* views in regard to these very important issues. I am frankly discouraged by all the talk talk talk, surveys, questionnaires, personal interviews, announcements etc. that preempted the NO LESS THAN THREE ANNOUNCEMENTS 2012, 2013 and 2014 that "this or this service" had been set up (especially targeted at those isolated, confined to home, vulnerable and frail persons within the community) or e.g. the start of a regular telephone conference between all those working in different capacities - medical, social, therapeutic - with certain identified vulnerable patients and who would then (with the patient's prior agreement) liaise with each separate service provider with a view to rationalising and improving the "service package" being offered to each individual patient. Promises, promises ... but the every day reality in my own experience very rarely delivers .. I nevertheless have the highest regard for all those professionals working at the coal face and who are often officially overseen by line managers/administrators monitoring every nuance and minute detail of their "performance" in the field/department, given "targets" to be met, unrelated to the personal professional relationship of the service provider and the 'client' but directed to the source of some obscure statistical or official analysis, subsequently printed out and published in multi-coloured close-printed charts and official reports for the delectation of those who stare at computer screens and key in all these reports, charts and data all day...

I thank you for your patience and, I hope, understanding of my present personal very real concerns not only for [REDACTED] but also for all those, perhaps less articulate or as noisy as I, who nevertheless **greatly value the outstanding facilities of the purpose built Haynes Centre (from funds bequeathed by the late Haynes sisters, private benefactors) and the CARING INVALUABLE CONTRIBUTION MADE BY THE PRESENT DEDICATED STAFF, THE INSPIRATIONAL LEADERSHIP/MANAGEMENT AND COMMITMENT demonstrated by Macqueen and his senior staff:** the friendly ambiance that is thus generated is a blessing that greatly benefits those whom we love and care for 24/7 365 days a year -

affording us the registered unpaid carers a few hours respite, confident in the knowledge that our dear ones are safe and cared for in a familiar environment, amongst friends - which affords a very rare if not unique opportunity for those suffering from RUTHLESS INCURABLE DISEASE to break free from the confines of their isolation, staring at the same four walls - and - for a while to enjoy the company of their peers and all the support workers. Most of us resist change .. but change to those whose lives are beset by anxiety, confusion and disorientation, who are battling dysphasia, the loss of memory, the inability to care for themselves, is, I passionately believe, a prescription for upset, even disaster - the like of which is a tsunami that destroys the relative stability and quality of their lives.

With the best of good wishes from your old constituent - who, although not a supporter of Labour politically, is confident that you will represent the interests of all Haringey's residents and tax payers

[REDACTED]  
[REDACTED] but please communicate by email/Royal Mail whenever possible.

Cllr Peter Morton  
Civic Centre  
High Road  
N22 4LE

1<sup>st</sup> October 2015

Dear Cllr Morton,

**Objections to Council's CP Priority 2 Proposals: The proposed closure of the Grange and the Haven Day Care Centres & the proposal to transfer the dementia day opportunities at the Haynes Day Centre to an external provider**

Summary of grounds for objections:

- Impact of proposed closures on the Haynes, service users and impact on carers
- Loss of capacity for specialist dementia care to meet current and future needs, the Haynes the sole service remaining
- Lack of clarity of re-assessment process, likely outcomes of reduced support and higher costs
- Lack of understanding of importance of transport to access services
- Lack of detail on proposed alternative services / suitability of provision in the community
- Lack of information on mid to long-term financial impacts for the users and the Council
- Lack of information and evidence to support proposals and hence inadequate consultation
- Inadequate involvement of users and/or carers in the redesign process

After several years of being ill my husband was diagnosed with early onset semantic dementia in [REDACTED]. He has been attending the Haynes since [REDACTED] 2010 since its opening, and for him it has become an extension of his home; he loves going to and being there and enjoys the company and friendship of the staff to whom he feels very close.

Dementia narrows ones physical and as well as social world dramatically, and attending Haynes helps hugely to mitigate that for him. I had to stop work in 2009 to look after him as he could not be left alone and could not look after himself.

In these very difficult years with this terrible illness the only bright light had been the Haynes, where he is well looked after feels secure and is stimulated so far as his ever diminishing capacity allows. Naturally I have the peace of mind that he is somewhere safe and somewhere he enjoys being while catching up with all his other care issues.

So I can say with some authority that the Haynes Day Care Centre is a place of excellence, with purpose built facilities and dementia trained experienced stable staff. This is of course recognised by others who over the years continue to visit the centre to learn from and share the experience. And over the years looking after him and his interests I almost became an expert myself, as many carers do, in dementia related things.

So it is with this background that I object strongly to the proposed closures of the Grange, another service of excellence, and the Haven where many with dementia are supported, and most concerned with the likely impact these closures will have on the service users and carers at the Haynes. I also strongly object to the proposed transfer of dementia day service at the Haynes to an external provider risking the sustaining of the excellence, risking the loss of expert staff, risking short-term gain but long-term costs, risking huge uncertainty for users, carers and staff.

The people with dementia need continuity, routine, stimulation in safe familiar surroundings supported by trained expert familiar staff if needs for more costly services are to be delayed.

Specialist day centres provide an important preventative service helping to maintain their wellbeing and helping them continue to live in their homes longer. I know that many carers at the Haynes would share these concerns and views, discussed at regular support group meetings.

The proposals and their impacts are contrary to Haringey's Corporate Plan Priority 2 Objectives, Dementia Commissioning Strategy, Equality Policies, and the Government policies as they are contained in the National Dementia Strategy, The Care Act and the NICE guidelines.

Please see below further detailed points supporting the objections to the proposals.

Kind regards,



### **Detailed points supporting the objections to the proposals**

#### **1. Impact of proposed closures on the Haynes, service users and carers**

The consultation paper states that "The proposal to close The Grange would require the reassessment or review of the care and support needs of current service users with a view to identifying satisfactory alternative provision to meet the assessed needs... there will be a transition plan which could involve support at the Haynes Day Centre." The Grange Day Centre is a specialist service supporting 17 service users per day with dementia assessed to be at the significant and critical level, who lack the capacity for independent living relying on others for their needs. They have complex needs and are unlikely to find satisfactory alternative provision in the community.

There are 18 service users per day at Haynes Day Care Centre, close to its design capacity of 20 users per day. As it is likely that most Grange users are assessed to need dementia day care services and/or require transition at the Haynes it would not be possible to accommodate them without impacting the service quality and without impacting the current service users. If the Haynes becomes the sole day centre for dementia and, if after reassessment very few users are found to have reduced level of needs, damaging service reductions would be imposed on many current users and their carers at the Haynes and/or the Grange contrary to their needs. We are concerned that the reassessment or review criteria would be made to reflect the number of places at the Haynes. We are also concerned that assessments or reviews may be carried out by people who are not familiar with dementia, contrary to The Care Act provisions which state that assessors must have a good knowledge of the person's condition.

The proposed closures of the Haven Day Centre, where up to half users have dementia would have similar impacts and put further pressure on the Haynes to the detriment of care to its current users.

#### **2. Lack of information on alternative provision / suitability of provision in the community**

The Council recognises that there are people with complex needs who require specialist services. People with dementia with a degenerative condition are in such a group requiring specialist services. Since all users of the Grange and the Haynes are clinically assessed as having severe dementia, it is unlikely that further assessments will find their needs are met by a lesser non specialist alternative provision. Demographic projections and improving diagnosis rates indicate that dementia numbers would rise significantly increasing demand

for such specialist services. The proposed closures cannot be justified if such current as well as long-term needs are to be met, and costly alternatives are to be avoided.

The consultation papers state that the council will move away from building based day opportunities but does not explain how specialist dementia day services can be provided within this approach.

People with dementia need familiar secure calm places with appropriate facilities, and this cannot be achieved without good purpose designed spaces. It is not building-less if care is simply moved to people's homes.

The Council's proposals rely on new untested and/or yet to be defined or developed new models of services. The Council provided no evidence that these new models would meet the current needs let alone the future demand. Although there is no objection to providing a wider range of services, it is very important that they are in place, proven to meet current needs and proven to have the potential to meet future demand before closures are considered if adequate support to the service users and their carers are to be secured.

The Council has not provided any information on the availability, and we are not aware of alternative specialist dementia day opportunities in Haringey. The proposed new models cannot substitute specialist services.

### **3. Impact of proposals on carers**

Where access to comparable adequate and satisfactory support is not available and/or not secured the carers not only loose the limited respite they get, they would have to take on more responsibilities to fill the gap created by the closures and service changes.

In addition to their severe or critical dementia limiting mental or physical abilities, over 65% of the service users at the Grange and the Haynes are over 80 years or over, over 60% have a physical frailty or sensory impairment; as such most will not have the capacity to manage their personal budgets or manage accessing support, they would have to rely on their carers. This would be an additional burden on the carers.

The Care Act has given the carers some hope that their needs would be supported, but we are concerned that impact of the proposals on carers are not taken into account.

### **4. Transport provision and travel times**

The Haynes is located to the western edge of Haringey. Any future service users from the east of Haringey will have long journeys limiting the time they spend at the day centre reducing benefits of attending the Haynes. The Grange should be retained to provide the specialist day service needed in the east of Haringey.

Currently all day centres provide transport. Accessing suitable alternative provision, even if they are / become available, would not be possible without transport provision leading to social isolation, loneliness and loss of quality of life both for the service users and their carers impacting their health and wellbeing.

### **5. Lack of information on financial impacts**

The Council provided no information on the cost and financial impacts of its proposals on the users, the Council or other service providers, e.g. NHS, short and long-term.

The consultation papers state that 'more services can be provided with less financial input from the council, but provided no evidence or information to support this assertion.

It is important to acknowledge that service users with dementia and/or complex needs who attend centres, rather they are complementary. Without day centres service users would be isolated and their health and care would be compromised. They are likely to need a lot more costly support services much earlier. The health and wellbeing of their carers are also likely to be impacted to need greater and costlier support.

The Consultation papers state that service users will be encouraged to use Personal Budgets to access any support required to meet assessed need. However it is not clear how the personal budgets would be set, whether they would be sufficient to secure comparable or adequate quality and quantity of support. Information is not provided to clarify the cost implications of the proposals for the service users.

## **6. Inadequate consultation**

The Council promised that "Where major changes to service users are proposed after budget setting, detailed plans will come forward and decisions will only be made after much more detailed consultation" (Para 7.1.4 of Item No 819 of 10 February 2015 Cabinet). This was reiterated by the EqIA produced to support the proposals. The consultation on proposed closures and service changes, and the subsequent co-design process, were completely inadequate and would not meet the *minimum* requirements for a statutory consultation.

No information on the type, shape and quantity of alternative or future provision, no information on the level of need, the re-assessment process, no information on timescales for change or no information on the community capacity are provided by the Council for a proper consideration of the proposals and their impacts.

The EqIAs that were produced are incomplete and inadequate, they do not fully identify impacts e.g. human and financial impact of closing the day centres. There is no information on how long-term needs are to be met.

## **7. Transferring the dementia day service at the Haynes to an external provider**

The Council provided no information on the type, shape and quantity of alternative or future provision, no information on the level of need, no information on timescales, or any evidence that an external provider will be appropriate to meet the needs of people with severe dementia, any evidence of a successful sustainable example of an external provider. The Council provided no information in support of an external provider being able to deliver a satisfactory comparable service while producing a surplus taking into account Council's current subsidy and current costs to service users. How is this to be achieved?

- i) by increasing costs to service users and/or introducing charges e.g. transport
- ii) by reducing costs that would impact quality of service, e.g. lower wages, untrained short term staff, overcrowding, lower staff/user ratio, loss of stimulating activities, loss of person centred activities and care, ready-made meals, etc. The Council provided no information on what would happen if the external provider is unable to continue.

The Council provided no evidence to support its statement that transferring the service at the Haynes Day Centre to a social enterprise would have minimal impact on existing carers and service users. The co-design process has been a narrow, superficial exercise with minimal input from users or carers.