

## HARINGEY COUNCIL ADULTS SOCIAL SERVICES 90-DAY CONSULTATION

### **[Priority 2: Empower all adults to live healthy long and fulfilling lives]**

#### Learning Disability Experience [LDX] Transformation Independent Advocacy Services Facilitation Outcomes Report



<b>Project Title</b>	<i>Haringey Council Adults Social Services (HCASS) 90-day Consultation – Corporate Plan Priority 2: empowering all adults to live healthy, long and fulfilling lives</i>
<b>Service</b>	<i>Learning Disability Experience (LDX) Transformation Independent Advocacy Services (TIAS)</i>
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## GLOSSARY

<b>Advocacy</b>	An independent service that takes action to help people say what they want, secures their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support, promote social inclusion, equality and social justice.
<b>Advocate</b>	The member of staff who supports the Service User (and their carer) to have their needs and wishes met and carried out in such a way as if they had spoken for themselves. A person of integrity and good character to represent the Service User/carer independently.
<b>Carers, Family Carers or Parent Carers</b>	A carer is anyone who cares, paid or unpaid, for a family member, a friend or other person who is in need of assistance and/or support with their daily living due to illness, disability, a mental health problem, an addiction or other ailment and cannot cope without their support.
<b>Core Requirement</b>	Obligation to do something in a form prescribed by the commissioner.
<b>Council or Local Authority</b>	Means Haringey Council or other Borough Councils.
<b>Key Stakeholder</b>	Key Stakeholders are individuals, groups or organisations that are affected by the activity of any service, activity or business.
<b>Measure</b>	The means to evaluate an outcome.
<b>Must</b>	Means that the activity referred to is Mandatory and /or Statutory required by Law.
<b>Outcome</b>	The expected end result to a process or completion of a work activity in the form of an output.
<b>Personal Data</b>	Means data as defined by the Data Protection Act 1998 which relates to a living individual who can be identified from such data and other information which is in the possession of, or is likely to come into the possession of You and opinion about an individual and any indication of the intentions in respect to an individual.
<b>Policy</b>	Is a set of general statements, which help staff and individuals to make sound judgments.
<b>Procedure</b>	Is the method by which a Policy is put into practice.
<b>Proposal</b>	A plan or suggestion, especially a formal or written one, put forward for consideration by others.
<b>Service Provider</b>	A person or organisation that provides any form of health, social and/or community care service.

<b>Service User or User of Service</b>	Anyone who receives any form of health, social and/or community care services. Also known in this report as the customer or the resident.
<b>Specification</b>	A set of instructions, presented in the form of a plan that provides the information needed to produce, build or develop a service.
<b>Staff</b>	The employees, workers and contractors and volunteers who carry out the Service Provision.
<b>Statutory sector</b>	Publicly funded bodies or organisations that include the local Council, NHS, public health and or any other organisation or body set up and funded by Government.
<b>Volunteer</b>	A person who performs a service voluntarily to do charitable or helpful work without pay.

## 1 INTRODUCTION AND BACKGROUND

### 1.1 Haringey Council Adult Social Services [HCASS] 90-Day Consultation. Corporate Plan Priority 2: empowering all adults to live healthy, long and fulfilling lives

#### The last three years:

Haringey Council's Corporate Plan, **One Borough, One Future 2013 – 2015** set the Council's priorities and outcomes, which were underpinned by five principles:

- One Borough Focus
- Investing in prevention and early intervention
- Promoting equality
- Empowering communities
- Working in partnership

These principles have been used over the last 3 years to inform service aims and objectives, delivery and outcomes.

#### What has happened already?

**Priority 2** of the new Haringey Draft Corporate Plan **Building a Stronger Haringey Together** requires Adult Social Services to: 'Empower all adults to live healthy, long and fulfilling lives'.

The current service delivery model must be transformed to ensure compliance with the Council's statutory obligations within their financial targets, ensuring services operate as efficiently and effectively as possible.

Haringey Council's vision is to create greater focus on self-management, prevention and early intervention for their customers. The core principle is to deliver services based on putting the service user, family and carers at the centre of their solution. This requires the redesign of existing service delivery models to facilitate:

- Recent legislative changes that provide opportunity for further integration of care and support services to improve outcomes and maintain people in their communities for as long as possible.
- New National policy directives which are aimed at empowering people to be independent.
- The growing demand for Adult Social Care services within the borough.

Initial proposals for the transformation of Haringey Council's service delivery model were submitted and open to a 30-day consultation from 17<sup>th</sup> December 2014 to 18<sup>th</sup> January 2015.

LDX were commissioned by Haringey Council Adults Social Services to provide independent advocacy and facilitation to help explain anything that was unclear and provide expert advocacy assistance to their less able customers/residents in responding to the above consultation at following corporate and specialist sessions. These were attended by users of services, carers and supporting staff as well as Councillor Peter Morton (Cabinet Member for Health and Wellbeing) and Beverley Tarka (Interim Director of Adult Social Services).

Haringey's Council Cabinet met on February 10<sup>th</sup> 2015 to recommend a budget to Full Council. This budget was agreed on February 23<sup>rd</sup> 2015. As a result of this agreement it was decided that due to the level of impact on service users and/or groups of service users, the proposals should be subject to a more detailed consultation before any final decisions can be made.

## What has recently happened?

Haringey Council's Corporate Plan for 2015-18 'Building a Stronger Haringey Together' sets out their overall priorities and programme of work for the period for 2015-18, it identifies supporting all adults to live healthy, long and fulfilling lives as one of its five priorities.

The Corporate Plan goes on to define specific objectives under each of its five priorities. These objectives extend our pledge; to build strong communities, empower residents to make healthier choices, intervene early, safeguard vulnerable adults and provide responsive and high quality services.

To meet these challenges the Council needs to transform the delivery of care and support. This means changing the way that they work, to continue to deliver services that ensure equity for those assessed as needing care and support.

Haringey Council's vision is to create greater focus on outcome focused pathways, prevention and early intervention for customers. The core principle is to deliver services based on putting the service user, family and carers at the centre of their solution. This requires the redesign of existing delivery models to facilitate:

- Recent legislative changes that provide opportunity for further integration of care and support services to improve outcomes and maintain people in their communities for as long as possible
- New National policy directives which are aimed at empowering people to be independent
- The growing demand for Adult Social Care services within the borough.

Haringey Council wants to ensure:

- a) Service users and their carers are fully aware how the proposals would affect them and gather their views;
- b) They work with service users and their carers to facilitate their views for the co-design of the new service provision.

Haringey Council's Corporate Plan summarises the Council's objectives as:

- Outstanding for all
- Clean and safe
- Sustainable Housing, Growth and employment

These objectives underpin the 5 priorities for the Council for the next 3 years:

**Priority 1:** Enable every child and young person to have the best start in life, with high quality education.

**Priority 2:** Empower all adults to live healthy long and fulfilling lives.

**Priority 3:** A clean and safe borough where people are proud to live.

**Priority 4:** Drive growth and employment from which everyone can benefit.

**Priority 5:** Create homes and communities where people choose to live and are able to thrive.

These priorities, in particular Priority 2, are used to inform the aims, objectives and delivery of services within Adult Social Care.

As a result of Full Cabinet's decision to agree the recommended budget a 90-day Consultation was instigated.

Updated proposals for the transformation of Haringey Council Adults Social Care (HCASS) service delivery model were submitted and open to consultation from 3<sup>rd</sup> July 2015 to 1<sup>st</sup> October 2015.

The Council did this to ensure that their users of services and their carers are aware of the proposed changes, how the proposals would affect them and to gather their views.

Haringey Council will consider your responses after 1st October 2015 when the consultation ends. The Adults Social Care Service will give their report to the Council's Cabinet, along with other information including the LDX Feedback Report and a final decision will be made in November 2015.

The Cabinet decision/outcome from the 90-day Consultation will be published in November/December 2015 along with any further actions required on the Haringey website.

## 2 PROJECT DETAILS

### 2.1 Summary Project Specification

After a lengthy tender, LDX were commissioned by Haringey Council Adults Social Services (HCASS) to provide independent advocacy and facilitation to help explain anything that is unclear and provide expert advocacy assistance to their less able customers/residents in responding to the 90-day consultation at the following Carers Focus Groups and Service User Workshops - July 2015 dates [Fig 1] and August 2015 dates [Fig 2]. These were attended by users of services, carers, supporting staff, corporate leads and Cabinet Councillors including Councillor Peter Morton (Cabinet Member for Health and Wellbeing).

The independent advocates helped people to express their wishes and feelings, support them in weighing up their options and assist them in making their own decisions regarding the service proposals.

The individual advocacy arrangements were agreed at a preliminary meeting between Haringey Council and LDX where the requirements of the brief and the service provision were fully explained. The specification did not determine a set or minimum period of advocacy provision for each individual and was flexible and responsive to need regardless of person or care group.

A full breakdown of the outcomes [which include details of the feedback and comments of customers, residents, users of services, carers as represented at the Focus Groups and Workshops] is provided by LDX to Haringey Council Adult Social Services in the form of this report.

**Fig 1: Carers Focus Groups and Service User Workshop Dates for July 2015**

Dates (July 2015)	Group	Times	Venue	Attendance
Thursday 16/07/2015	All LD Carers (1)	11:00-1:00	Ermine	17 carers 9 staff (26)
	All LD Carers (2)	5:30-7:30	Ermine	
Monday 20/07/2015	Ermine SU	10:00-2:00	Ermine	8 SU's 1 carer 7 staff (16)
Wednesday 22/07/2015	OGNH Carers	5:30-7:30	OGNH	12 carers 1 cllr (13)
Thursday 23/07/2015	Always and Birkbeck SU	10:00-2:00	Birkbeck	17 SU's 5 staff 2 carers (21)
Friday 24/07/2015	Haynes and Grange Carers	10:30-12:30	Haynes	14 carers 1 cllrs (15)
Tuesday 28/07/2015	OGNH SU	10:00-1:00	OGNH	6 service users 3 staff (9)
	Linden SU	3:30-5:30	Linden	4 carers 1 staff (5)
Wednesday 29/07/2015	Roundways SU	1:30-3:30	Roundways	10 carers 7 staff (17)
	Haven carers	5:30-7:30	Haven	20 carers (20)
Thursday 30/07/2015	Haynes SU	10:30-12:30	Haynes	6 carers 2 SU's (8)
	Grange SU	2:00-4:00	Grange	7 carers 10 SU's (17)
Friday 31/07/2015	Haven SU	10:00-12:00	Haven	20 SU's 3 carers 3 cllrs (26)
Total Numbers				<b>196</b>

**Fig 2: Carers Focus Groups and Service User Workshop Dates for August 2015**

Date (August 2015)	Group	Times	Venue	Attendance
Monday 10/08/2015	Always and Birkbeck SU	10:00-2:00	Birkbeck	8 carers 2 residential staff 1 Cllr (11)
Wednesday 12/08/2015	Ermine SU	10:00-2:00	Ermine	6 SU's 2 carers 5 staff (13)
Friday 14/08/2015	OGNH SU Linden SU	10:00-1:00 3:30-5:30	OGNH Linden	3 service users, 2 staff (5) 1 carer 5 staff 1 Cllr (7)
Monday 17/08/2015	Haynes SU Grange SU	10:30-12:30 2:00-4:00	Haynes Grange	3 carers 2 staff (5) 11 SU's 8 carers 1 Cllr 5 staff (25)
Tuesday 18/08/2015	Haven SU	10:00-12:00	Haven	22 SU's 5 carers 6 staff (33)
Friday 21/08/2015	Roundway SU	1:30-3:30	Roundway	3 carers 2 staff 1 Cllr (6)
Additional Telephone Sessions				2 Carers
<b>Total Numbers</b>				<b>107</b>

**OGNH** – Osborne Grove Nursing Home **SU** – Service Users **LD** – Learning Disabilities

Attendance Data	Users/Carers	Others	Total Numbers
July 2015	148	48	196
August 2015	74	33	107
	<b>222</b>	<b>81</b>	<b>303</b>

Advocacy/Consultation	Focus Groups/Workshops	Other	Total
July 2015	31 hrs	36 hrs	67 hrs
August 2015	21 hrs	34 hrs	55 hrs
			<b>122 hrs</b>



## 2.2 Scope and Beneficiaries

The commissioned independent advocacy and facilitation was made accessible and accountable to all vulnerable people and carers who approached LDX and Haringey Council to engage, who are residing in Haringey Council and come from all wards within the borough.

Approachable recipients did not need to meet the Fair Access to Care Service (FACS) eligibility criteria for adult's health and social care services as the Council has taken into account those groups that did not meet the criteria but required support such as those identified as low or moderate..

Individuals and groups were assisted to:

- Understand the proposed changes to Haringey's Adult Social Services and involved spending considerable time with people, taking into account their communications needs, their wishes and feelings and their life story, and using all this to assist them to be included and where possible to make decisions.
- Communicate their views, wishes and feelings during the consultation.
- Challenge a decision or process made by the local authority; and where a person cannot challenge the decision even with assistance, then to challenge it on their behalf.
- Decide what outcomes/changes they want
- Understand what advice and help they can expect from others.
- Understand what parts of the process are completely or partially within their control.

## 2.3 Haringey Council Adults Social Services Consultation Audience

Haringey Council sought the views, experiences, comments and concerns of customers, residents, users of services and carers of those using adult social care services in relation to **Priority 2: Empower all adults to live healthy, long and fulfilling lives.**

In spite of any possible challenges, timeframes and the consultation exercise itself, LDX has most certainly sought to give a voice to vulnerable adults within Haringey's diverse borough paying particular attention to hearing from those who may be seldom heard, as well as those who may be isolated.

LDX supported the remit to hear from as many individuals as possible within Haringey Council and paid particular attention to people with learning disabilities, the elderly, those living with dementia and their carers as per the requirements.

At any one time the support LDX provided focused on accessibly reaching out to those identified above. This was done in the format of wider consultation and specific discussions.

To support people with non-verbal communication and/or limited understanding LDX also accessed people identified as 'circles of support' such as family members, carers, residential care support, programme coordinators, team leaders, care workers, assistant managers and managers. This was to stringently seek their views [as individuals who know the users of services best] for the sole purpose of speaking up on their behalf. This was done through group meetings and 1:1 conversations.

LDX user engagement was robust and credible and we have fully demonstrated our professionalism, knowledge, appropriate skills level and competencies throughout the process; required to deliver the requested functions to the highest possible level to achieve the Haringey Council specification.

## 2.4 Independent Advocacy

An advocacy service is provided by an advocate who is independent of social and health services. Being independent means they are there to represent people's wishes without giving their personal opinion and without representing the views of the local authority or any other services.

Many local councils and some hospitals fund local advocacy services to support people, particularly those who are vulnerable in the community. For wider issues which impact on all people, groups and services from the same community the assistance of external independent advocacy may be required.

Independent advocacy should always be separate from any service provision, its staff, users of services, families, carers and any stakeholders directly or indirectly involved with or affected by service provision.

Therefore any advocacy support or facilitation must be independent and free from possible conflicts of interest.

Independent advocacy providers (individuals or organisations) should not be involved in the welfare, care or provision of other services to the individual for which they are providing advocacy.

Independent advocacy should be provided by an organisation whose sole role is independent advocacy or whose other tasks either complements, or do not conflict with, the provision of the independent advocacy requested. As such, Haringey Council Adults Social Services seeking external independent advocacy and facilitation has been a good action and best practice as it protects everyone involved against any probable implications.

For the purpose of the Haringey Council Consultation, LDX has been utilised as an external independent advocacy service to autonomously provide individuals or groups with the information they need so they can make real choices about their circumstances.

LDX Independent Advocacy:

- Puts people first.
- Is accountable.
- Is as free as possible from any conflicts of interest.
- Is accessible.

LDX:

- Supports individuals or groups to put their choices and wishes across to others and to speak on their behalf when they are unable to do so for themselves.
- Represent the views of individuals or groups.
- Protect individuals or groups who are particularly vulnerable to make informed decisions.
- Feedback an issue raised by individuals or groups to service providers as part of any decision-making process and so that services can be constantly improved to meet the needs of the growing market.

In addition and where appropriate independent advocates may also:

- Support an individual/group in seeking resolution to issues which concern them.
- Help to safeguard the rights of individuals or groups.
- Empower individuals or groups to make informed decisions and to take greater control over their lives.

## 2.5 Contact

For all matters concerning the outcomes in this report and anything in relation to the Haringey Council Adults Social Services consultation please contact:

**Haringey Council Social Services**

40 Cumberland Road, Wood Green, London N22 7SG

- Donna Simeon, Transformation Project Manager [donna.simeon@haringey.gov.uk](mailto:donna.simeon@haringey.gov.uk)

### 3 EQUAL OPPORTUNITIES MONITORING

The Public Sector Equality Duty does not expressly require the Haringey Council to collect equality information. However, collecting, analysing and using the information helps them to see how their policies and activities are affecting various sections of their communities.

As such LDX attempted to collect information from the **219** people we spoke to either individually or as part of a group and who have a range of abilities.

It is very important to stress that the monitoring of these people was done so anonymously. Therefore all of the figures collated can only be accepted as an impression of the demographics of those we spoke with. Of the **219** service users and carers who we consulted with:

- ~ Some people did not provide accurate information.
- ~ Some people gave more than one response in a single category.
- ~ Some people came to more than one meeting and may have provided a monitoring form each time.
- ~ Not everyone completed the form fully or answered every category.
- ~ Others chose to completely abstain from providing a form.
- ~ Some people did not get the opportunity to complete a form.
- ~ Some people in attendance who were neither service users nor carers may have completed a monitoring form too.

#### Wards

	Service User	Carer/Family Carer		Service User	Carer/Family Carer
Alexandra Ward	0	2	Northumberland Park Ward	4	5
Bounds Green Ward	0	3	St Ann's Ward	3	2
Bruce Grove Ward	3	1	Seven Sisters Ward	5	3
Crouch End Ward	1	2	Stroud Green Ward	3	3
Fortis Green Ward	0	1	Tottenham Green Ward	2	5
Harringay Ward	6	13	Tottenham Hale Ward	9	4
Highgate Ward	2	6	West Green Ward	10	3
Homsey Ward	6	14	White Hart Lane Ward	4	2
Muswell Hill Ward	4	6	Woodside Ward	0	0
Noel Park Ward	1	2	Unspecified on form	21	12

## Identification

	Service User	Carer/Family Carer
Male	38	17
Female	56	38
Gender Reassignment	0	0
Unspecified on form	22	8

## Which service do you use or does your loved one use?

	Service User	Carer/Family Carer		Service User	Carer/Family Carer
Always Day Centre	5	8	Linden Road Residential		7
Birbeck Road Day Centre	4	16	Osborne Grove Nursing Home	8	5
Ermine Road Day Centre	5	11	The Haven Day Centre	41	13
Grange Day Centre	13	22	The Roundway Day Centre	0	11
Haynes Day Centre	2	19	Other or Unspecified on form	0	18

## Age Group

	Service User	Carer/Family Carer
Under 20	0	0
21-24	0	0
25-29		1
30-44	2	7
45-59	7	44
60-64	5	15
65-74	17	11
75-84	7	2
75-84	14	6
85-89	9	2
90 and over	6	0
Unspecified on form	16	11

## Disability

	Service User	Carer/Family Carer
Deafness or partial loss of hearing	4	2
Blindness or partial loss of sight	3	2
Learning Disability	7	7
Developmental disorder	0	0
Mental ill health	12	3
Long term illness or condition	30	10
Physical disability	25	9
Other disabilities	1	7
No disabilities	4	7
Unspecified on form	12	48

## Pregnancy and Maternity

Are you pregnant or have you had a baby in the last 12 months?	Service User	Carer/Family Carer
Yes	0	0
No	52	63
Unspecified on form	19	43

## Language

	Service User	Carer/Family Carer
Albanian	0	0
Arabic	0	0
English	50	66
French	0	4
Lingala	0	0
Somali	0	0
Turkish	0	0
Other	5	6
Unspecified on form	24	34

## Ethnicity

	Service User	Carer/Family Carer
White British	14	22
White Irish	3	3
Greek/Greek Cypriot	1	3
Turkish/Turkish Cypriot	0	1
Gypsy/Roma	0	0
Kurdish	0	0
Irish Traveller	0	0
White and Black African	1	1
White and Black Caribbean	4	6
White and Asian	0	1
Indian	3	3
Bangladeshi	0	0
Pakistani	0	0
East African Asian	4	1
African	6	6
Caribbean	27	1
African Caribbean	0	0
Chinese	0	0
Any other ethnic background	3	17
Unspecified on form	9	22

## Sexual Orientation

	Service User	Carer/Family Carer
Heterosexual	48	66
Bisexual	0	0
Gay	0	0
Lesbian	0	0
Prefer not to say	4	8
Unspecified on form	21	35

## Religion

	Service User	Carer/Family Carer
Christian	53	75
Hindu	3	2
Muslim	0	1
Sikh	0	0
Methodist	0	0
Jewish	1	0
Rastafarian	0	0
Buddhist	0	0
Other Religion	3	3
No Religion	3	4
Prefer not to say	0	0
Unspecified on from	13	18

## Marriage and Civil Partnership

	Service User	Carer/Family Carer
Single	8	23
Married	21	34
Co-habiting	0	2
In a same sex civil partnership	0	0
Separated	0	0
Divorced	12	10
Widowed	19	5
Unspecified on from	12	32



110 people were identified as 'Circles of Support' these were made up of carers and staff. Circles of Support for users of services helped individuals and groups of people with learning disabilities, dementia, older people and other vulnerable groups to speak up for themselves and/or they spoke up on their behalf during the consultation sessions. Councillors also came to observe and listen to what people had to say.

### Circles of Support

	Staff	Carer/Family Carer		Staff	Carer/Family Carer
Always Day Centre/Birbeck Road Day Centre	7	10	Linden Road Residential	6	5
			Osborne Grove Nursing Home	5	0
Ermine Road Day Centre	12	3	The Haven Day Centre	6	8
Grange Day Centre	5	15	The Roundway Day Centre	7	10
Haynes Day Centre	2	9	Other or Unspecified	0	0

### Observers/Councillors in attendance

	Carers Focus Groups	Service User Workshops 1 & 2		Carers Focus Groups	Service User Workshops 1 & 2
Always Day Centre	0	1	Linden Road Residential	0	1
Birbeck Road Day Centre	0	1	Osborne Grove Nursing Home	1	1
Ermine Road Day Centre	0	0	The Haven Day Centre	0	3 (at both )
Grange Day Centre	1	1	The Roundway Day Centre	0	1
Haynes Day Centre	1	1	Other or Unspecified	0	0

### In addition to the above:

- Senior Representatives from within the Haringey Council Adults Social Care Department attended all Carers Focus Groups and some Service User Workshops.
- An extra meeting was held for Carers of people with learning disabilities to provide them with the opportunity to meet with Councillor Morton outside of our consultation meetings.

## 4 METHODOLOGY

### 4.1 Council Proposals

Haringey Council's Corporate Plan for 2015-18 'Building a Stronger Haringey Together' sets out five priorities and programmes of work for the period for 2015-18. Corporate plan priority 2: Empowering all adults to live healthy, long and fulfilling lives is the priority used to inform the aims, objectives and delivery of services within Haringey Council Adult Social Care.

Haringey Council consulted with the public on specific proposals to transform Adult Social Services; paying particular attention to hearing from key stakeholders who may directly be affected by the proposals including adults who currently use identified services and their carers.

The 90-day Consultation ran from Friday 3<sup>rd</sup> July 2015 to Thursday 1<sup>st</sup> October 2015. Consultation information was made available on Haringey Council's website and sent in the post. Stakeholders were given a number of ways for them to have their say and/or return their completed feedback.

- Online
- E-mail
- By post
- Carers Focus Groups
- Service User Workshops

**The 3 proposals being considered are:**

- **Proposal 1:** To increase the Council's capacity to provide re-ablement and intermediate care services. This affects Osborne Grove Nursing Home and Haven Day Centre.
- **Proposal 2:** Increasing our capacity to provide suitable accommodation that promotes individual well-being through expanding Supported Living Accommodation and Shared Lives Schemes. This affects Linden Road Residential House
- **Proposal 3:** Increasing the availability and flexibility of day opportunities within the borough meeting the individual need of residents. This affects Ermine Road, Roundways, Birkbeck and Always Day Centres; the Grange Day Centre and the Haynes Day Centre.

At all 20 meetings, everyone was given the opportunity to consult on all 3 proposals. However, the majority of people who attended these Carers Focus Groups and Service User Workshops were very focused on expressing their views about the specific services that affected them or their loved ones as identified by Haringey Council Adult Social Services (HCASS) as proposed for closure or significant change.

Within each group of attendees there was a mix of knowledge concerning the proposals. Service Users and Carers were either:

- Very knowledgeable about all 3 proposals.
- Only clued up about the proposal that affected them or their loved ones.
- Had no understanding or knowledge of any of the proposals and only came because they had received a letter or as part of a service user group.

Regardless of people's knowledge base all in attendance had very different interpretations of what the proposals meant in reality. This was evident in the discussions held at the meetings and in the feedback gathered. LDX also spent considerable time (with support from Haringey Council Leads) reading the proposals and explaining them in much detail before people felt comfortable to respond or express their views.

Many people also expressed great concerns that the proposals were very jargonistic, lacked transparency and were difficult to meaningfully interpret. For the proposals that were presented Carers raised issue with the vision for Personal Budgets and the fact that there were no alternative services offered to offset any proposed closures or changes. As such people struggled to accept that the above are proposals and believed that they had already been actioned.

Overall it was very clear that people wanted to talk about proposed closures and significant changes to service provision, as the bulk of the feedback will show. As such, the outcomes from the consultation sessions are set out by affected services with general comments at the end.

**Figs 1 and 2** of the Summary Project Specification [2.1] identify the timetables for the Focus Groups and Workshops.

All people who LDX consulted with agreed the following:

- ✓ I have learned something about the consultation that I did not know before.
- ✓ I enjoyed the discussion.
- ✓ I have been able to say what I wanted to say.
- ✓ I have felt listened to.
- ✓ I felt respected during the sessions.

## 4.2 LDX Consultation Questions

### Carers Focus Groups:

LDX asked the following questions to people at Carers Focus Groups. To keep in line with Haringey Council's consultation **ALL** questions asked required one of the subsequent responses. This was followed up with further questions to seek clarification to why people chose a particular response.

- ✓ Strongly support
- ✓ Support
- Neutral
- X Do not support
- X Strongly do not support

### Carers Focus Groups – Osborne Grove Nursing Home

<b>Proposal 1:</b> To increase the Council's capacity to provide re-ablement and intermediate care services.	<b>Question 1:</b> Do you support Haringey Council's proposal to: <b>A:</b> Close Osborne Grove Nursing Home and change the use to intermediate care facilities? <b>B:</b> Continue with the current provision at Osborne Grove Nursing Home, transfer the existing service provision to an external provider and to include a re-ablement care service?	<b>Question 1 (sub question):</b> Please tell us why you feel this way?
	<b>Question 2:</b> Do you support Haringey Council's proposal to transfer the internal re-ablement service to an external provider?	<b>Question 2 (sub question):</b> Please tell us why you feel this way?

### Carers Focus Groups – The Haven Day Centre

<b>Proposal 1:</b> To increase the Council's capacity to provide re-ablement and intermediate care services.	<b>Question 3:</b> Do you support Haringey Council's proposal to close the Haven Day Centre?	<b>Question 3 (sub question):</b> Please tell us why you feel this way?
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### Carers Focus Groups – Learning Disability (Ermine Road, Roundways, Birkbeck and Always Day Centres and Linden Road Residential Home)

<b>Proposal 2:</b> Increasing our capacity to provide suitable accommodation that promotes individual well-being through expanding Supported Living Accommodation and Shared Lives Schemes.	<b>Question 1:</b> Do you support Haringey Council's proposal to close Linden Road Residential Home?	<b>Question 1 (sub question):</b> Please tell us why you feel this way?
	<b>Question 2:</b> Do you support Haringey Council's proposal to provide more accommodation options promoting individual wellbeing through Supported Living and Shared Lives Schemes?	<b>Question 2 (sub question):</b> Please tell us why you feel this way?
	<b>Question 3:</b> Do you support Haringey Council's proposal to transfer the Shared Lives service to a social enterprise?	<b>Question 3 (sub question):</b> Please tell us why you feel that way?
<b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.	<b>Question 1:</b> Do you support Haringey Council's proposal to close Roundways, Birbeck Road and Always Day Centres for adults with learning disabilities?	<b>Question 1 (sub question):</b> Please tell us why you feel this way?
	<b>Question 2:</b> Do you support Haringey Council's proposal to provide a new model of day opportunities from Ermine Road Day Centre through an alternative provider	<b>Question 2 (sub question):</b> Please tell us why you feel this way?

## Carers Focus Groups – Haynes and Grange Day Centres

<b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.	<b>Question 3:</b> Do you support Haringey Council's proposal to close the Grange Day Centre?	<b>Question 3 (sub question):</b> Please tell us why you feel this way?
	<b>Question 4:</b> Do you support Haringey Council's proposal to transfer the dementia day opportunities at the Haynes Day Centre to an external provider?	<b>Question 4 (sub question):</b> Please tell us why you feel this way?

## Service User Workshops One and Two

LDX held two Service User Workshops per affected service group over the months of July and August 2015 consecutively. Each workshop had questions specifically relating to their services.

All of the service users who attended the Workshops needed support to express their views about changes to their services in one way or another.

The following services saw service users speaking up for themselves with support from staff or their carers. Questions were adapted to enable meaningful engagement and for people to fully participate. Where appropriate, objects of reference and pictures were also used to support involvement and understanding.

- Osborne Grove Nursing Home
- The Haven Day Centre
- Always and Birbeck Day Centre
- Ermine Road Day Centre
- The Grange Day Centre

Service users from the remaining services have severe disabilities and conditions that does not permit them to fully understand the proposals nor speak up for themselves. (Apart from 2 people) carers and staff represented their views and spoke up on their behalf as part of a variety of Circles of Support.

- Linden Road Residential Home
- Roundways Day Centre
- The Haynes Day Centre

## Osborne Grove Nursing Home ( Service users and Circles of Support – Staff)

<b>Proposal 1:</b> To increase the Council's capacity to provide re-ablement and intermediate care services.	<b>Question 1:</b> Do you support Haringey Council's proposal to: <b>A:</b> Close Osborne Grove Nursing Home and change the use to intermediate care facilities? <b>B:</b> Continue with the current provision at Osborne Grove Nursing Home, transfer the existing service provision to an external provider and to include a re-ablement care service?
	<b>Question 2:</b> What activities do you currently enjoy/do at the home or in the local community with support?
	<b>Question 3:</b> Who helps to support you in the home?
	<b>Question 4:</b> If 'A' of Question 1 is agreed by Cabinet as the way forward then current residents who live at Osborne Grove will not be expected to leave. However, if you had your own money (a personal budget) to spend on care services would you choose to: 1) Continue to live at Osborne Grove? 2) Would buy something different? (Alternative Care) 3) Or would you mix it up? (Care at home and in the community?)

## Linden Road Residential Home (Circle of Support – Carers and Staff)

<b>Proposal 2:</b> Increasing our capacity to provide suitable accommodation that promotes individual well-being through expanding Supported Living Accommodation and Shared Lives Schemes.	<b>Question 1:</b> Do you support Haringey Council's proposal to close Linden Road Residential Home?
	<b>Question 2:</b> Do you support Haringey Council's proposal to provide more accommodation options promoting individual well being through Supported Living and Shared Lives Schemes?
	<b>Question 3:</b> Do you support Haringey Council's proposal to transfer the Shared Lives service to a social enterprise?
	<b>Question 4:</b> What activities do the residents currently enjoy/do at the home or in the local community with support?
	<b>Question 5:</b> How would you feel if it was different people helping/supporting the residents to do the activities they enjoy?
	<b>Question 6:</b> If the residents have their own money (a personal budget) to spend on care services would they choose to: 1) Continue buying a service like Linden? 2) Choose something different? (Alternative care) 3) Or would they mix it up? (a bit of the old and something new?)

## Always and Birkbeck, The Haven and the Grange Day Centres (Service Users and Circle of Support – Carers and Staff)

<p><b>Proposal 1:</b> To increase the Council's capacity to provide reablement and intermediate care services.</p> <p><b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.</p> <p>(Objects of Reference and Pictures were used to support understanding of the questions)</p>	<b>Question 1:</b> Do you support the closure of the day centre?
	<b>Question 2:</b> What activities do you currently enjoy/do at the centre or in the local community with support?
	<b>Question 3:</b> Who helps to support you at the day centre?
	<p><b>Question 4:</b> If you had your own money (a personal budget) to buy services or activities would you choose to:</p> <p>1) Continue buying a service like what the day centre offer?</p> <p>2) Would you choose something different? (Alternative care)</p> <p>3) Or would you mix it up? (a bit of the old and something new?)</p>

## Ermine Road Day Centre (Service Users and Circles of Support – Carers and Staff)

<p><b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.</p> <p>(Objects of Reference and Pictures were used to support understanding of the questions)</p>	<b>Question 1:</b> Do you support Haringey Council's proposal to make changes to your day services?
	<b>Question 2:</b> What activities do you currently enjoy/do at the centre or in the local community with support?
	<b>Question 3:</b> Who helps to support you at Ermine Road?
	<p><b>Question 4:</b> If you had your own money (a personal budget) to buy services or activities would you choose to:</p> <p>1) Continue buying a service like what the Ermine Road offer?</p> <p>2) Would they choose something different? (Alternative care)</p> <p>3) Or would they mix it up? (a bit of the old and something new?)</p>

## The Roundway Day Centre (Circle of Support – Carers and Staff)

<p><b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.</p>	<b>Question 1:</b> Do you support the closure of the day centre?
	<b>Question 2:</b> What activities do the service users currently enjoy/do at the centre or in the local community with support?
	<b>Question 3:</b> Who helps to support service users at the Roundways?
	<p><b>Question 4:</b> If the service users had their own money to spend on care services (a personal budget) would they choose to:</p> <p>1) Continue buying a service like what the Roundways offer?</p> <p>2) Would they choose something different? (Alternative care)</p> <p>3) Or would they mix it up? (a bit of the old and something new?)</p>

## The Haynes Day Centre (Service Users and Circles of Support – Carers and Staff)

<p><b>Proposal 1:</b> To increase the Council's capacity to provide re-ablement and intermediate care provision to an external provider and to include a re-ablement care service?</p> <p><b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.</p>	<p><b>Question 1:</b> Do you support Haringey Council's proposal to transfer the dementia day opportunities at the Haynes Day Centre to an external provider?</p>
	<p><b>Question 2:</b> What activities do the service users currently enjoy/do at the centre or in the local community with support?</p>
	<p><b>Question 3:</b> Who helps to support service users at the Haven?</p>
	<p><b>Question 4:</b> If the service users had their own money to spend on care services (a personal budget) would they choose to:</p> <ol style="list-style-type: none"> <li>1) Continue buying a service like what the Haynes offer?</li> <li>2) Would they choose something different? (Alternative care)</li> <li>3) Or would they mix it up? (a bit of the old and something new?)</li> </ol>



## 5 FEEDBACK FROM HARINGEY COUNCIL ADULTS SOCIAL SERVICES 90 - DAY CONSULTATION – PRIORITY 2: EMPOWER ALL ADULTS TO LIVE HEALTHY, LONG AND FULFILLING LIVES

The following comments are the acquired independent views and opinions of residents, customers, service users, carers and stakeholders living in Haringey or accessing services from Haringey Council Adults Social Services.

Unless explicitly stated, the independent views, opinions and/or comments from and of the above individuals or groups **do not** reflect those of the organisation Learning Disability Experience [LDX] or any of its staff members.

### 5.1 PROPOSAL ONE: To increase the Council's capacity to provide re-ablement and intermediate care services.

#### Carers Focus Groups – Osborne Grove Nursing Home

12 Carers attended this meeting. 6 Carers **do not support** proposals A or B. 6 Carers **strongly do not support** proposals A or B. All 12 Carers want Osborne Grove to be left as it is.












<b>Proposal 1:</b> To increase the Council's capacity to provide re-ablement and intermediate care services	<b>Question 1:</b> Do you support Haringey Council's proposal to: <b>A:</b> Close Osborne Grove Nursing Home and change the use to intermediate care facilities? <b>B:</b> Continue with the current provision at Osborne Grove Nursing Home, transfer the existing service provision to an external provider and to include a re-ablement care service?	<b>Question 1 (sub question):</b> Please tell us why you feel this way?
	<b>Question 2:</b> Do you support Haringey Council's proposal to transfer the internal re-ablement service to an external provider?	<b>Question 2 (sub question):</b> Please tell us why you feel this way?

#### Proposal A: Carer – Osborne Grove



"There has been a promise that people will stay for their lifetime. What kind of guarantee is there that people can stay...things change? Would Haringey council still take part in the service if it went private? Even with regards to the facility itself it's second to none in London. It will be a shame if it is closed down. There will be pressure on the health service."

### Proposal A – Osborne Grove Carers said:











-  You need more nurses. Limited nurses. I am scared about what has been happening in private homes. We have seen it in the press. Too much change is not good for elderly people...changes of staff, changes of the way things are.
-  I think that staff should go to resident's rooms more often. I do not want an external provider. I don't know what kind of service elderly people will get?
-  Why are so many things being 'cut'? Why do you keep changing things to Wood Green High Road, 4 times in 20 years and you keep taking things off old people? Why is it always old people? Is it because they don't matter?
-  I think what would make the things much clearer would be to get a consultant into Osborne Grove to be able to see what the business could look like. The Council could then take a view on if they wanted to keep it.
-  How are you going to get over the loss of nursing beds in Haringey? It isn't just about the people who are at Osborne Grove now it's about what will happen for people in the future. It is likely that people will be shipped out to Enfield and Barnet.
-  You need an independent consultant to come in to look at a business plan. Nursing homes are a simple business but we are not experts in that area...we just know about our relatives. We can sit on a panel but not be the panel.
-  How are you going to keep Osborne Grove going if you have 2 people left after everyone's gone but they live for 20 years? How are you going to afford that? If you get private people coming in the nature of the place will change.
-  I am a person who thinks that because we are only being given 2 options the decision has already been made. This is the second time that me and my brother have moved my mother. I think it is a shame to close the last residential home in the Borough. Why can't Haringey leave things alone? Manage things properly and invest?
-  I am a carer and a resident. I am here and my wife is here. I like this place for a start, but someone has to look after my wife, I can't do it. There comes a time when you can't. I don't know anything about homes, councils, nothing. The person who would have known would be my daughter. I like it here. It's a home. I might have another 4-6 weeks but I like it here and I don't have any other home to go to. Why are you holding meetings in the middle of the day for residents? People who work can't get here for these meetings.
-  Closure is the wrong terminology; it feels fixed. Osborne Grove is good and unbroken, why fix it?
-  How can you solve the problem of the lack of nursing beds? What's going to happen to next wave of people who need nursing care? How will nursing beds be provided in the Borough?

### Proposal B: Carer – Osborne Grove



“Private providers coming in the back door would be the beginning of the end for Osborne Grove. I have major concerns about who would come in, what they would do when they get here and what that would mean for loved ones? We all think the same and have the same view. Will the new organisation roll up their sleeves or just wear cuff links?”

### Proposal B – Osborne Grove Carers Said:

-  Quality care would go down. When the new people start it would be good but eventually it will slowly go downhill.
-  What are the economics of how it works? This seems like a ‘sweetheart deal’ by the Council as there are so few beds in Haringey because of rents and costs.
-  Not sustainable long-term solution because of land costs. Who is going to come into the nursing home? People with money that who and what’s going to happen for those who cannot pay.
-  This is not sustainable. Social services will run it in a more business like way. I do not believe in external providers and cannot manage a social barrier. Why can’t the Council manage this and get the right people to run Osborne Grove?
-  I’m happy to house re-ablement but not if it’s outsourced.
-  A lot of the initiatives have gone wrong. We don’t know if you are asking the right questions and confidence is not there in terms of any consultation. Bring the critical people together; people who are experienced. Get them to look at the situation.
-  Why is it that private companies make profit? Why can’t the council look after their own? If you’re going to do this then get proper business people in, make a profit and keep things running.
-  This is so unjust to have to look at private companies.
-  Carers need to be on a body to interview the new organisation. Is it a social entity?
-  Why not get business people to run the council. Bring the people together those who have the skills.

- 💬 I do think it is important to have people who have been through it on the process of recruiting an external provider.
- 💬 Once private companies come in that would be the end – one foot in then slowly, slowly they'll change it; destroy it. Do these external people have a proper track record is there resources to check them out?
- 💬 There is a change of purpose – with intermediate care. Can it work with getting different people in the home? Will it change it completely?
- 💬 Who would monitor and take control? They would be left to their own needs.
- 💬 If it would be cheaper the private company would increase costs to make profits.

#### **General Comments – Osborne Grove Carers Said:**

- 💬 The confidence isn't in this consultation.
- 💬 The decision has already been made.
- 💬 These are not options for me?
- 💬 Haringey should leave things as it is and manage properly.
- 💬 We need to keep our permanent staff not have agency.
- 💬 All of this is a waste of money. Leave things alone and let things carry on as it is.
- 💬 You need to get a business minded person in Haringey.
- 💬 Private company is for profits; the council is for the people.
- 💬 Will cost more money
- 💬 Don't the Council care anymore about quality of care?
- 💬 The Council is conflicting two different issues. Finances and people's health and wellbeing.
- 💬 The Council need to support local businesses.
- 💬 Initiatives have gone – don't know whether you're asking the right questions.
- 💬 How are you going to pay for it?
- 💬 I would agree if I knew there was a benefit but there isn't any.
- 💬 The fundamental question is what's going to happen?
- 💬 The broader picture is that Osborne Grove are not the only ones, other interested groups have to be taken into consideration too?
- 💬 We don't have the expertise to judge this.
- 💬 As only two options have been given I think a decision has already been made.
- 💬 These are not really options.

## Service User Workshops 1 and 2 – Osborne Grove Nursing Home

9 Residents in total attended these Workshops.

Proposal A – 7 Residents **strongly do not support**. 2 Residents were **neutral**.

Proposal B – 3 Residents **support**. 4 Resident **strongly did not support** and 2 Residents were **neutral**.

<b>Proposal 1:</b> To increase the Council's capacity to provide re-ablement and intermediate care services.	<b>Question 1:</b> Do you support Haringey Council's proposal to: <b>A:</b> Close Osborne Grove Nursing Home and change the use to intermediate care facilities? <b>B:</b> Continue with the current provision at Osborne Grove Nursing Home, transfer the existing service provision to an external provider and to include a re-ablement care service?
	<b>Question 2:</b> What activities do you currently enjoy/do at the home or in the local community with support?
	<b>Question 3:</b> Who helps to support you in the home?
	<b>Question 4:</b> If 'A' of Question 1 is agreed by Cabinet as the way forward then current residents who live at Osborne Grove will not be expected to leave. However, if you had your own money (a personal budget) to spend on care services would you choose to: <b>1)</b> Continue to live at Osborne Grove? <b>2)</b> Would buy something different? (Alternative Care) <b>3)</b> Or would you mix it up? (Care at home and in the community?)

### Resident – Osborne Grove



"Are you sure that the level of care that they want to bring is good? Has the Council tried it? They should try being seriously ill some time. Maybe they might think twice. Will there be the same level of staff? If you change the management will we get the same staff?"

### Option A – Residents said:

The level of care that people receive could be much lower. This could be because of funding and equipment and priorities. Also I'm wondering what will happen to those in the intermediate care who are not well enough to leave after 6-8 weeks or who need to be moved to a facility like what we have now (Nursing Home)?

☞ The need isn't going to go away because people are still going to need long term care and this is the last of the Haringey nursing homes.

☞ What are our rights for the people who currently live here? Where will we be legally? What will happen to us and people like us who live here now. Will we still get the same level of care? What will be our terms and conditions. Will they still be the same? Will we still get the same support from nurses and staff? What are our legal and safeguarding rights? Who will look out for our wellbeing?

### **Option B – Residents said:**

☞ I don't know if Haringey will fund it to the extent that the new providers will be able to meet costs because some local authorities have a shortfall in what they pay per resident. I heard something on the radio that some care homes are closing because they can't meet the costs because Local Authorities' set a figure of what they're going to give and it doesn't meet the costs of running the home. So standards will fall or they will have to shut.

☞ How will this be funded because there may not be enough money?

☞ Don't know how many short term beds will be available. We could go on for a long time. If it means that we would get the same level of care then it wouldn't be so bad. I don't know how that would impact on our care.

☞ I don't like the idea of it being sold? Because private companies don't pay very well and you don't get the right level of staff. Some local authorities don't pay the home owners very well. I've been to a private provider before. I don't know what they intend to do with the place.

### **What activities do you currently enjoy/do at Osborne Grove or in the local community with support?**

☞ I shouldn't have to justify what I do here for them to keep Osborne Grove. This is not a day centre. This is my home. I live here. I do what everyone else does in their home. Eat, drink, wash, sleep, join in activities, read and listen to the radio. Sometimes I do nothing at all. What do you do in your home?

☞ People come in to play instruments. Sing songs that you remember so that you can join in.

☞ Art, painting and pottery. Sometimes I leave and go shopping.

☞ I'm not here that long so I can't tell you about many things but I think the others are right. However, whatever activities are happening I join in. I am in a better position. Many times I go out to the library and the day centre and the garden centre at wolves lane. Wood Green shopping mall.

☞ I enjoy listening to the radio and watching television. Prefer radio to television. I'm a late night person. I stay up late.

☞ My lifestyle is different to the other people. I must see the news every day. I read the newspaper. Sun or Daily Mail. I like Sunday papers.

☞ I watch television. I enjoy TV especially if it's Star Trek.

☞ I stay here but this is not my home. I haven't tried to go out. Only go out to see the doctor or visit hospital frequently.

- 💬 If there done in a convenient way that helps me I will listen to the music when people come. Like the steel band.
- 💬 I'm not interested in music or other stuff.

### Resident – Osborne Grove



"Staff means a lot to us. We have developed friendships as well. Staff tends to stay. Not a high turnover. The advantage to this in developing trust. Friendship is important to everyone. I think the staff are marvellous. If I was on the outside and I would be able to see the care they give."

### Who helps/supports you at Osborne Grove?

- 💬 Is there anything special that OG offers - The personal care is special. I need a great deal of personal care and I can only get it in a place like this.
- 💬 This place was built for us. I didn't know anything about care homes until I came here. I think it serves a good purpose.
- 💬 I've been here a couple of years I don't have the authority to talk about it? I agree with whatever the ladies say because any of them could be my wife. I don't know?
- 💬 I don't care anything about the staff or the other 'prisoners'. I'm anti-social. I'm not interested in making friends with anyone. I was perfectly happy in bomb disposal taking risks. Petrol tank bombs and other bombs. It's never been the same for me since. **(This person genuinely worked in the army in bomb disposal)**

**If 'A' of Question 1 is agreed by Cabinet as the way forward then current residents who live at Osborne Grove will not be expected to leave. However, if you had your own money (a personal budget) to spend on care services would you choose to:**

- 1) Continue to live at Osborne Grove?
- 2) Would buy something different? (Alternative Care)
- 3) Or would you mix it up? (Care at home and in the community?)

8 Residents said they wanted to stay at Osborne Grove. 1 Resident refused to answer the question.

- 💬 This is like the PowerStation that I used to work in. Meetings, meetings, meetings. And when they finish they still do what they want and strike.
- 💬 I don't like either option really. I just want things to stay as they are. When you are very dependent it makes me feel unsettled.

- ☞ The questions are similar and they're only trying to put us in a boat. "You did say 'yes' or 'no', so what are you complaining about. If they want to change it to different management then just say so. If they want to close it then just say so. If they want to do this tomorrow it will change.
- ☞ They offer great facilities here. The level of care is good. They need to leave it alone.
- ☞ Does that mean that they might teach me to walk again?
- ☞ I couldn't give a stuff. Don't care because I don't want to be in a home. I don't care so long as I have television. Totally indifferent to the options.

## Carers Focus Groups – The Haven Day Centre

20 Carers attended this meeting. All 20 Carers **strongly do not support** the proposal to close the Haven Day Centre.

1 Councillor also attended.

<b>Proposal 1:</b> To increase the Council's capacity to provide reablement and intermediate care services.	<b>Question 3:</b> Do you support Haringey Council's proposal to close the Haven Day Centre?	<b>Question 3 (sub question):</b> Please tell us why you feel this way?
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### Carer – The Haven



"A concern that people are in it for the money. The council is looking to rewrite its obligations in statue to elderly people. This process is geared to shifting its responsibility and this will cost more."

### Carers Said:

- ☞ They do not know what we as carers do. This is not just about our loved ones, it's also about us. We need help. We need time off from caring. I help my mother, I am not officially registered with the council and I do not get paid.
- ☞ This must have been thought of for some time? A pilot scheme should be done so that they can see that it will be a major crisis. The Council is not looking at the wide range of needs. It's not just people with dementia. It's people with Alzheimer's, Parkinson's, Diabetes, physical disabilities. I cannot see how the proposal will work as all have different needs.



- ☞ People are being pushed back into their homes. I have given up my job to look after my disabled husband. I need a break too. The council cannot pass on its statute responsibility. With the new care act the carer has the same rights as the user.
- ☞ It's taking the piss. Has anyone thought that people will be sat in doors 24hrs a day? But what are they going to do? Will we be able to phone someone out of hours? They will be limited to do only certain things.
- ☞ For me it's about my dad, he comes to the Haven. He enjoys coming to the centre. All his conversations are about the centre. I don't what he would do if he didn't come. He can't wait until Friday. He just loves everything about it, the people, the atmosphere is great. He'd stopped talking to us but now he is talking again. Even with his granddaughter he's having conversations. My mum passed in 2013, he was a shell. Once he came to the Haven he came out of his shell. He became independent again. My dad was adamant that he did not want a carer. He never did. That is why I am here 24/7. He wants his family.
- ☞ We have a relative who attends. No doubt there are other places she can go but will the quality of care and friendship be the same? No matter how poorly she is, she is up and ready to go.
- ☞ The staff are very good for the service users. The interaction is important. Before she came to the Haven she was in hospital or stuck in her room talking to the TV. Now she comes back talking to us about things she did at the day centre.

#### Carer – The Haven











"When my relative is at the day centre I know she is not only secure but I know that she is looked after. The carers visit 15-30 minutes in the home. At the haven she is here for 4-5hours. Home carers don't notice anything. The Haven carers phone if she is not well or check that her wheelchair is working properly. I totally trust the judgment of the Haven carers."

- ☞ Individuals have individual needs. The staff knows when someone is 'not right'. They spend time with them because they understand. My dad knows to trust the staff here. He may not remember their names but he knows their faces. When the bus is due to collect him he is ready at the window looking out.
- ☞ I look after my sister. She comes once a week. She wishes it was more. One day is not enough. She decides what she is wearing, she needs her jewelry and her perfume and then she is ready. She cares so much about the people she is going to meet. Both of us live in a flat 24/7. It gives us both a break. You get to concentrate on the things that need to get done.
- ☞ We are talking about different abilities and some who cannot use public transport, if something happens who is responsible? Taxi drivers do not understand conditions.

- 💬 We feel very strongly that the Haven should stay. We don't want strangers coming in to our homes. My son will be upset too.
- 💬 I would like a feasibility study on people who use the Haven and might benefit from a reablement service?
- 💬 I had a job looking after disabled children. I had to give it up to care for my husband.
- 💬 Private care costs more. You could also almost mirror the arguments in the NHS and the cost of agency nurses. The Council wants to legally retain their statutory obligations but pay someone else to do the work.
- 💬 If Haringey up my workload I will be in serious trouble.
- 💬 Need to look at way the haven works. I can ring the haven for my sister in law and everything is sorted. She can spend the day at the haven rather than going out for a coffee for an hour. She will have a meal and her medication.
- 💬 Will what is written actually happen in practice?
- 💬 When an agency worker came, we do not know the carer, its different people all the time. Then you have to show them what to do so we might as well not have them at all?
- 💬 Why can't you do a pilot before closing all the centres it will be a crisis and the council have not looked at the broad needs. It's called being limited. Everyone has different needs.
- 💬 Regardless of whether we are talking about the Haven, Linden Road, the council are looking to re-write their obligation under the statute to shift responsibility. This is just another way of getting private companies to come in which will cost the Council more in the long run. All the affected people who are going to be pushed back into the home will require family to care for them. This means in a different way people will be claiming more money.
- 💬 You are looking at this as if people are able. Social isolation is a real issue. All this is easy to say but very difficult to do. You need to do a feasibility study. What is the ethos of the centre? Why it work and reassessment does needs to be done before the decision to close not after. An assessment does not resolve issues.
- 💬 When my brother comes home he feels good and enjoyed the day and I (carer) can get on with my life and do things at home.
- 💬 This is a huge disruption of people's lives who have been at the centre for months and years. What can you offer them?
- 💬 Even though they are changing from Council to other services it puts pressure on me as a 24/7 carer. Agency carers don't arrive on time, don't come at all or don't know the needs of my family member. I might as well look after them myself?
- 💬 My relative has x4 Care per day. 6:00pm my sister called saying no carer had turned up. We had to rely on the neighbour to give the medication. In contrast I can ring the Haven ... is she at the Haven? Has she had her medication? Has she had a meal? Yes, yes, yes. She is diabetic. She can go hyper. The Haven solves much of this; we know she is safe, fed and well.

## General Comment – Haven Carers

-  Distressed
-  Devastated
-  Terrible
-  Worried
-  Don't close – distraught
-  Not happy
-  Stressed
-  Concerned

## Service User Workshops 1 and 2 – The Haven Day Centre

**Workshop 1 – 20 Service Users, 3 Carers and 3 Councillors.**

**Workshop 2 – 22 Service Users, 5 Carers and 6 Staff.**

<p><b>Proposal 1:</b> To increase the Council's capacity to provide reablement and intermediate care services.</p> <p><b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.</p> <p>(Objects of Reference and Pictures were used to support understanding of the questions)</p>	<p><b>Question 1:</b> Do you support the closure of the Haven Day Centre?</p>
	<p><b>Question 2:</b> What activities do you currently enjoy/do at the Haven or in the local community with support? (sub question) Are you asked and given choices about the activities?</p>
	<p><b>Question 3:</b> Who helps to support you at the Haven? (sub question) What would be the impact on you if The Haven closed? (This question is for both carers and users)</p>
	<p><b>Question 4:</b> If you had your own money (a personal budget) to buy services or activities would you choose to:</p> <ol style="list-style-type: none"> <li>1) Continue buying a service like what the Haven offer?</li> <li>2) Would you choose something different? (Alternative care)</li> <li>3) Or would you mix it up? (a bit of the old and something new?)</li> </ol>

### Service User – The Haven



“The people who use this service (the users) have paid taxes over the years. The people will be isolated; by coming here their mind is active and is able to converse with others and the wider family. This service is really needed for this age group otherwise a lot of elderly people will be demanding higher support needs and the immediate family would not be able to cope. This is keeping the family unit together.”

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## Do you support Haringey Council's proposal to close The Haven Day Centre?

### All 44 Service Users – Strongly do not support

- 💬 This service is only important to those who use it and their families so it's not important to the wider community who is not concerned about the service.
- 💬 If this centre closes and this man who uses this service either kills himself or others then I will hold the council responsible.
- 💬 This place is very important for each and every one of us, they teach us how to control our mind and be active - boredom is the greatest killer.
- 💬 This gives me something to do and think about
- 💬 This is my second home - do not want to go anywhere. I look forward to coming here, my family work and if I didn't come here then they would have to give up work.
- 💬 I don't have anyone and I look forward to coming here, I am very lonely.
- 💬 Paid carers do not have time to spend with you, they do what they need to do and go.
- 💬 I just need to know what is there out there for people like us?
- 💬 I have a bus to get me here and drop me back. I can't use public transport.
- 💬 If this is closed he will become lonely, added pressure on me and will not be able to cope.
- 💬 How many others are sitting at home but can't come due to lack of transport, they took away one of the bus from the centre.
- 💬 Carers have their own need
- 💬 There's such a great demand for this type of service so why are they doing this???
- 💬 The money should be spent on the demand for this service and project plan ahead.
- 💬 Is there more realistic costing for personal budget - logistic transport, meals etc
- 💬 Rather than looking at cutting the service the council should be looking at promoting and expending the service.
- 💬 Carers are not being taken serious and our elderly are not valued by the council who do not care about us.
- 💬 By coming here the carers get a little respite, we are able to recharge ourselves to enable us continue.
- 💬 If I am sad or if I have a problem then I can share this at the centre and I get a pick me up and it makes me feel better.
- 💬 No provision available for people like us. Not acknowledgement from A – Z.

## Service User – The Haven



“The staff are aware of each and every ones needs, when S.U are down they are able to lift their spirits and shake of the blues, staff have knowledge and history of the individuals, Staff are able to raise safeguarding concerns, keep an eye on individuals, almost like preventative measures to ensure the elderly are safe.”

”

- ☞ The carers are disabled themselves.
- ☞ The move to support in the community or in the home is not suitable for my husband.
- ☞ Alleviates isolation, mind is kept active.

### What activities do you currently enjoy/do at The Haven or in the local community with support?

- ☞ Getting out of the house
- ☞ Trips out
- ☞ Holistic approach
- ☞ Empathy
- ☞ no one to play dominos with
- ☞ scribble
- ☞ quizzes
- ☞ puzzles
- ☞ special shops

### Are you asked and given choices about activities?

- ☞ At all time. We are taken on trips out with our carers so that we have quality family time.
- ☞ When I first came here, my dentures were broken and the staff supported me to get things sorted out.
- ☞ During Christmas we have 3 days of lunches and we go to want see the lights.
- ☞ We also celebrate other customs and religions - all being respected and celebrated.
- ☞ We do not consider any types of ethnicity - we are all friends
- ☞ National citizenship group - 4 sessions over the year
- ☞ I have a disabled daughter, with my own disability was not able to see her but the staff supported me from here.
- ☞ There is also is a memorial garden here for those who have passed on, it's very family orientated.
- ☞ We have one of our user's ashes out there, it was her wish.

### Who helps/supports you at the Haven?

- ☞ Staff is wonderful.
- ☞ Councillor Bull plays karaoke.
- ☞ The ex-Mayor, is a volunteer and comes here.

- 💬 The paid staff.
- 💬 Councillor Peacock pays for all users to go to the Poppy Appeal Service for the ceremony.
- 💬 Sharing memories and group discussions with people here.
- 💬 You can't moan about our children with your children - we share things here.
- 💬 We're similar ages and have lots of things in common and this will be lost when they close our centre.
- 💬 The calibre of staff and professionalism is superb.
- 💬 I have trust in them and this place works especially when we have been let down by so many professionals.
- 💬 He would do 2 days if he didn't get too exhausted. The heavy burden and pressure is on me and my family.

**What would be the impact on you if The Haven closed? (This question is for both carers and users)**

- 💬 Social isolation.
- 💬 Children wouldn't be able to go to work.
- 💬 Finance will be hard.
- 💬 Wouldn't be able recoup and recharge batteries in our caring role.
- 💬 It allows me to care for immediate family as they are side-lined when I'm caring for my mum.
- 💬 I don't want to be a burden on my children and this centre is important to me as it gives them a break.
- 💬 Independent, enrich people's lives and giving people something to talk about. Whilst my mum is not home it gives me a chance to catch up on things otherwise I would be restricted in caring role. For example pay bill, get provisions etc.
- 💬 He would become depressed and introverted and would lose confidence.
- 💬 DC is aware of his disability but is in denial. He is unable to comprehend 3 months of his life.
- 💬 Impact on family would be catastrophic as the time for me or the other members of the family would be lost just to catch up on either house work, shopping, paying bills.
- 💬 I'm struggling because I'm very emotional about this. We don't want it to go. This is my second home. Strange people coming in my home. I will end up going back to where I was in the first place.

**If you had your own money (a personal budget) to buy services or activities would you choose to:**

1. Continue buying a service like what the Haven offer? (If it didn't close)?
  2. Would you choose something different? (Alternative care)
  3. Or would you mix it up? (A bit of the old and something new?)
- 💬 It is beautiful here; the staff are very kind to us
  - 💬 Personal budget only pays for attendance and does not pay for others things such as food or transport. I think this is a loaded question and is unfair to talk about.
  - 💬 It would be insane to close the service. Can't the reablement service be added like an add on to what is currently provided.
  - 💬 You're talking about holistic care via enablement but in reality this does not happen for our elderly.
  - 💬 The Haven do fundraising from arts and crafts, which is used to buy gift for user at Christmas and also a lunch because some do not have family and this makes a big difference to individuals.
  - 💬 I do not want centre to shut.
  - 💬 Coming here has changed my life.
  - 💬 I enjoy being here.
  - 💬 I meet my friend here and we go out together.
  - 💬 The sort of care provided here would cost far more than what is provided here.

- 💬 If this was put to a public vote this place would not close.
- 💬 Closing this centre will not bring us happiness.
- 💬 I and my fellow users will chain ourselves to the gates, sit outside and will even hire electric scooters and chase the councillors away.
- 💬 How will individuals adjust when enablement ceases especially when in your 70,80,90
- 💬 Can't possibly be right for very body
- 💬 People look forward to coming here. Where will people go when they close the centre?
- 💬 DO NOT CLOSE OUR CENTRE.
- 💬 Even if we have personal budget we don't want someone young with nothing in common with us to takes us out. We want to be with our age group of people.
- 💬 Continue to use the Haven. We don't see another alternative, as this service is invaluable. You wouldn't get a service like this anywhere.
- 💬 We already been through hell and the reality of the haven closing would mean we are back to square one. This gives us one day a week respite. by having someone come into our home would not work as this is our sanctuary and having strangers invading it would not be conducive to DM;s needs. At least he is getting some interactions here and he is well cared for. This place is vital for our community.
- 💬 When you're working and have a caring responsibility the effect of not having a service to fall back on puts pressures on you physically and mentally.
- 💬 By going to centre like this gives us peace of mind, when he returns has different outlook. As carers gives them a break too. Quite short sighted to take a service like this away when we have an ageing community.
- 💬 This service is giving him the opportunity to mix and socialise with like-minded individuals.

## 5.2 PROPSAL TWO: Increasing our capacity to provide suitable accommodation that promotes individual well-being through expanding Supported Living Accommodation and Shared Lives Schemes.

### Carers Focus Groups – Linden Road Residential Home

A joint Learning Disability Carers Focus Group was held for Ermine Road, Always, Birbeck and Roundways Day Centres and Linden Road. 17 Carers in total attended. The responses below are what ALL carers said about the closure of Linden Road Residential Care Home.

Question 1: 14 **Strongly do not support**. 1 **Do not support** and 2 were **Neutral**

Question 2: 14 **Strongly do not support**. 1 **Do not support** and 2 were **Neutral**.

Question 3: 14 **Strongly do not support**. 1 **Do not support** and 2 were **Neutral**.

<b>Proposal 2:</b> Increasing our capacity to provide suitable accommodation that promotes individual well-being through expanding Supported Living Accommodation and Shared Lives Schemes.	<b>Question 1:</b> Do you support Haringey Council's proposal to close Linden Road Residential Home?	<b>Question 1 (sub question):</b> Please tell us why you feel this way?
	<b>Question 2:</b> Do you support Haringey Council's proposal to provide more accommodation options promoting individual wellbeing through Supported Living and Shared Lives Schemes?	<b>Question 2 (sub question):</b> Please tell us why you feel this way?
	<b>Question 3:</b> Do you support Haringey Council's proposal to transfer the Shared Lives service to a social enterprise?	<b>Question 3 (sub question):</b> Please tell us why you feel this way?





### Carer – Linden House

"I think moving people when they're settled is dangerous because they need stability continuity and a stable routine. Up routing them to new surroundings when where they do not know anyone and in a new community is dangerous. It's dangerous in terms of their health and wellbeing and their quality of life especially when we don't know who will be providing these new proposed services. Whatever way I look at this moves it does not make sense. Whatever argument is used the financial or quality of care argument in favour of the move does not make sense.

- 💬 My family went to a facility in Hampshire. He was progressing really well. Cost cutting meant that he moved to Linden. After so much distress from the move it has taken years for him to settle. Now you're going to do it to him all over again.
- 💬 It is cruel. Why do this when he is in his 50's? It is cruel to the family. It will affect my health. I'm already looking after my elderly brother who is very ill.
- 💬 Why close Linden after refurbishing it?
- 💬 Don't you people give a damn? It will be difficult for client to adjust in different places.
- 💬 It costs £450k to run Linden Road. This is a small amount of the overall budget. These people cannot be expected to look after themselves. There are very big differences in severity of disabilities for these residents compared to others.
- 💬 If the people at the top went to linden and saw the differences between that provision and supported living they would see that the proposal makes no sense.
- 💬 We do not want supported living services to be an either/or with day centre services. More supported living will exclude service users from other services and I am concerned about ongoing care as carers get older. There is also a high turnover in supported living – too many new faces. It is not designed or suitable for people with these severe needs.
- 💬 Linden should not be referred to as an institution.
- 💬 Independent living can leave people isolated - shared lives staff has minimal responsibilities if individual is not opening the door.
- 💬 It is a complex set of costs – one cut can cause other costs which will cost more overall.
- 💬 What is going to happen to staff? This is an exercise in cuts. Providers won't be given adequate resources to give a good service. All of these things have a knock on effect.
- 💬 We don't trust the Council to provide a quality service. There will be a high turnover of staff and they will be paid less than the minimum wage. It should be stipulated by the Council that all employees should be paid London Living Wage. There is also no guarantee that new employers will keep existing staff who the users trust. What happened to Care Continuity?



- 💬 We are worried that providers will have to provide replacement care.
- 💬 I am worried that when the new placement breaks down residents may return home with many associated problems. Nobody should be moved until an absolute satisfactory alternative is found.
- 💬 Vital service to clients. It needs to stay open. It's there because it needs to be there. If they close the place what happens to the residents?
- 💬 I agree with other housing schemes but there is also a place for residential accommodation.
- 💬 Supported housing works for some clients and is better for them.
- 💬 Do the service users want to leave? Has anyone asked them? They have formed relationships. All of the residents are there because the families have tried everything else.
- 💬 The expertise of the staff – what will happen to this? Not everyone could cope with learning disabilities and complex needs. They have special training.
- 💬 I haven't seen one parent carer who wants any LD centres or homes closed.
- 💬 We are not getting the support from the Council that we need as families. You are walking all over us. This is misleading. It feels like this is just a formality. This whole thing is an insult and a waste of our time.
- 💬 If Linden Road closes will the property be used to provide supported living?
- 💬 It should be up to the residents of Linden Road and their families to decide what is happening. I feel that these questions should be directed specifically at service users, carers, family and friends affected.
- 💬 I do not know anything about Linden Road and it does not affect my loved one. I feel that this does not give me the right to comment on this matter.
- 💬 Given the complexity of the clients will they be able to make this decision? Maybe with help from their families. There must be ways to get an opinion from the service users?
- 💬 There are various supported living providers out there. Private providers. Can the Council guarantee the skill base of these staff? My fear would be someone would end up with a member of staff with no experience.
- 💬 It takes years to make friends and be able to converse with staff. Changes will make them socially isolated. Alternative providers will not be aware of users' needs. It takes years to establish a rapport with our users.

## **Service User Workshops 1 and 2 – Linden Road Residential Home (Circle of Support – Carers and Staff)**

**Workshop 1 – 4 Carers and 1 Staff.**

**Workshop 2 – 1 Carer, 5 Staff and 1 Councillor**

<b>Proposal 2:</b> Increasing our capacity to provide suitable accommodation that promotes individual well-being through expanding Supported Living Accommodation and Shared Lives Schemes.	<b>Question 1:</b> Do you support Haringey Council's proposal to close Linden Road Residential Home?
	<b>Question 2:</b> Do you support Haringey Council's proposal to provide more accommodation options promoting individual well being through Supported Living and Shared Lives Schemes?
	<b>Question 3:</b> Do you support Haringey Council's proposal to transfer the Shared Lives service to a social enterprise?
	<b>Question 4:</b> What activities do the residents currently enjoy/do at the home or in the local community with support?
	<b>Question 5:</b> How would you feel if it was different people helping/supporting the residents to do the activities they enjoy?
	<b>Question 6:</b> If the residents have their own money (a personal budget) to spend on care services would they choose to: 1) Continue buying a service like Linden? 2) Choose something different? (Alternative care) 3) Or would they mix it up? (a bit of the old and something new?)




#### Carer – Linden House



"It doesn't make sense because Linden Road got good a CQC report and the residents and the family members are happy with what has been built here. They're being cared for properly and they appreciate that."

#### Do you support Haringey Council's proposal to close Linden Road Residential Home?

All 5 Carers - **Strongly do not support.**

-  The council has a duty of care that out ways any potential financial saving or cost benefit that may occur as a result of the proposed move. Also Linden Road got a really good CQC report so there is no reason to close it down. The care here is excellent. Everyone is settled here. I'm pretty sure linden isn't that expensive to run.
-  The financial argument – Linden Road is inexpensive to run. I have a ball park figure of how much it costs to run and its well within the Council's financial abilities so I don't understand why they are moving people.
-  Worst case scenario if this proposal goes ahead my parents would have to quit working which means less income would come into the family home. I would have to quit my studies and seek full time work to supplement the expenses. My parents are now pensioners and they have their own health issues. They are not the same age as when my brother was younger and they were able to

manage him. I would be worried about both my parents and my brother's health and wellbeing. If that happens I would be worried about who would support him in the future.

- 💬 He has been there since day one and if he was to move this will destroy him. He was the first resident there and has been there ever since. He knows the area, the home, the staff – he can't deal with the move.
- 💬 Haringey spring things on you at the last minutes and just send you a letter to tell you what the case is without us having a say.
- 💬 Why would you move someone over 50 years old, it effects the family significantly.
- 💬 Why did they choose to close linden Rd when they only refurbished the building a few years ago.
- 💬 Very upset lady that the home is closing.
- 💬 Disrupt people's lives by changing and moving people.
- 💬 Elderly herself who cares for her elderly brother and is now worried for their nephew in Linden House
- 💬 87 years old and who needs help herself. Her priority is not her support but help for her nephew in linden house.

**Do you support Haringey Council's proposal to provide more accommodation options promoting individual wellbeing through Supported Living and Shared Lives Schemes?**

**Do you support Haringey Council's proposal to transfer the Shared Lives service to a social enterprise?**

All 5 Carers - **Strongly do not support** either of the above proposals.

- 💬 Of the two options of supported living and shared lives schemes I'm not happy with either. Shared lives - research that I've done shows that it is for people with much milder conditions than what my brother has. My brother cannot do this. They need 24 hr specialist care.
- 💬 Supported living is closer to what he has now but my worry with this is the staff - who will they be? How will they be hired? Will it be temporary staff? My brother needs permanent staff that will be around on a permanent basis who understands him and can get to know him. That's what he has here now?
- 💬 I'm concerned about focus on integration into the community. The council is perpetuating this term. They just don't understand our loved ones when talking about employment or community based activities.
- 💬 He's been moved already. They said then that where he was, was too expensive. We experienced many anxieties then. We were told that the move to Linden Road was permanent because and when the letter came to say that they were closing Linden Road it came out of the blue and was a complete shock for us.

- 💬 Integrating people into the community is not a one size fits all. That's what it feels like. I don't think they are taking into account their complex needs of each individual. What they are proposing is not going to integrate them into the community it's going to alienate them from the community.
- 💬 There should be more supported living because I am unable to support my severely autistic son.
- 💬 Supported living = you won't get the same people caring for your son/daughter. You don't get the same person – how can they build relationships.
- 💬 There has to be some provisions for us when we cannot support
- 💬 Shared living staff – have minimal responsibility. There is NO accountability. Staff for shared lives is not always providing duty of care they should to the person in shared living scheme.
- 💬 The people are aggravated by changes and this will affect the carers as they become very hard to look after.

**What activities do you currently enjoy/do at Linden House or in the local community with support?**

- 💬 My brother attends the day centre twice a week. He likes using the sensory room. He enjoys long car trips because everything is new to him. He also likes wild life and gospel music.
- 💬 My brother is non-verbal but can express to people that he trusts what his needs are by leading people to things. He has his ways of communicating with us but it's not any universal language it's something that has to be learnt by people over a very long period of time. This could take months or even years to develop.

**Carer – Linden House**



"Worst case scenario people might leave him and then he will become isolated. When he was a child he used to go to a special school that wasn't equipped to look after him. They didn't have the staff. He became isolated walking up and down the corridors by himself. This is a massive concern. Someone might get frustrated and push him or lash out at him. That's why you can't have anyone around him.

- 💬 He becomes frustrated makes signs, may be liable bite become louder a pain sort of sound. in those in those instances there is very little to calm him
- 💬 Basic needs - two are happy to go to the day centre. The others do not enjoy the day centre and prefer to be around the grounds and go out into the community. Day centres are not deemed suitable for them as long periods and sessions causes anxiety. They do not like the interaction with lots of people. They all enjoy their music but they need space. They all enjoy spending time in the garden.

- 💬 All 5 residents have Log books which record their day such as personal care, moods, eating and drinking and bowel movement.
- 💬 One resident has a cake baking session on a Tuesday morning. It all depends on his mood. The neighbours were concerned about the noises coming from the house and used to come over to raise concerns.
- 💬 Not everyone has the capacity to do certain things. Persistent from staff has helped people to accomplish certain things.
- 💬 Foot Spa, Sensory, listening to music. We go out into the community i.e. Southend, park, forest. Basic isolated areas away from crowds. Animals don't bother them. They are aloof.
- 💬 One person initially came to Linden Road for respite and ended being here for over 4 years. Arrangements are now made for that person to return home. That was originally due to the deterioration at the home he lived in. Everything is now resolved. This move is outside of the consultation. He went to the Arsenal Game. Thoroughly enjoyed it. Spoke to the Arsenal Disability group.
- 💬 Only a couple of residents have slightly more capacity than others.

#### **Who helps/supports to support the residents at Linden House?**

- 💬 Staff, parent/carers, community learning disability team - offering activities, and concepts on new ways of doing activities, the day centres.
- 💬 Friends/residents. They are settled and have a fairly decent relationship with each other. Important dynamics between them.
- 💬 Staff, family and family with support from staff. I've seen my brother becomes distressed when service users leave the building for a significant time. This is why it's so important to keep these people together and to keep the community together. If this is disrupted this will not end in a good situation.
- 💬 Linden Road invited neighbours over to see for themselves. We have now built up relationships.
- 💬 Parents come to visit at different times between once a year to 3 times a week for different service users.

#### **How would you feel if it was different people helping/supporting the residents to do the activities they enjoy?**

- 💬 They would feel incredibly scared in this situation and we would be incredibly concerned for their health and wellbeing. You can't just throw any staff at this situation. They need to be qualified. We would not be pleased with this scenario. We want to avoid this at all costs.
- 💬 These new staff will not have the time or care to look after my brother. How far are these new staff prepared to go? Will they enjoy changing nappies and things like that? Are they prepared to go the extra mile? And more so for my brother he would be scared of a change like that. He wouldn't understand them and they wouldn't understand him.



### Carer – Linden House

“One resident would not have stayed here if it weren’t for our training. Slapped and kicked people. Take him in to an outside environment with strange people he will start hitting again. Continuity keeps him and other people safe. Same people, same building, same activities.”

- 💬 New staff might impose their way of doing things on my nephew and that’s not the way to care for him. That’s not how to work with my nephew that’s not going to help him.
- 💬 The residents would be very confused. They have been living in this environment for as long as they can remember. It’s harmful.
- 💬 Changing the environment will be difficult but the environment and the staff will be put them in crisis.
- 💬 Mum was never able to come on her own. Her son was negatively enthusiastic. Mum can now spend time with him on her own. It has been 7 years.
- 💬 All the factors have not been considered. What is the new environment like? It will be a huge shock to the system. What if it’s further away and family won’t be able to see them or they see family less and less?
- 💬 We have a good home life now. When my brother comes to see us he hangs around with us watching films and listening music. The frequency with which he can alternate between two settings is good. He won’t be able to come home for a long time if he moves because he will digress and his behaviour will become unmanageable for the family. This means he could lose both his homes.
- 💬 Anxiety and uncertainty that is going through my mind. Aunty is absolutely devastated. People have got into a comfort zone. They can sleep at night. They have been given an assurance that their loved ones are being taken care of. This will kill me.
- 💬 Someone who was here before and has moved on to another supported living - He has now gone and it appears as though he has gone backwards.
- 💬 If this isn’t handled particularly well you will have at least 3 people who’s life will be turned upside down. They will take steps backwards.
- 💬 I understand the reasons why some people are in these supported living but this is not for them.

**If the residents have their own money (a personal budget) to spend on care services would they choose to:**

- 1) Continue buying a service like Linden?
- 2) Choose something different? (Alternative care)
- 3) Or would they mix it up? (a bit of the old and something new?) Would you use it to continuing living at Linden House or would you use it to buy another service such as supported living, shared lives scheme, pay for a family/personal carer or something else?

💬 Linden House everytime?

💬 Personal carers couldn't handle him. Autism is one of those conditions which if you haven't been around it for a long time you don't understand it.

💬 It's not just a case of moving them in with their current resident peers it's about who else is going to be there (other peers)? What about staff will they be moved over as well?

💬 If you keep them together but not with the same staff then it's almost irrelevant. Keeping them together will only provide a small amount of comfort. People should not underestimate the value of the current staff. They will know their eating times and little intricacies. Staff and the family members know these things. Staff know how to treat everyone in relation to each other. These are

💬 things are going to take months or years to re-learn. This is why it is important to maintain stability remain calm and at peace. This only happens after a long period of trust building.

💬 The use of the word institution has too many negative connotations. The council are using it to prejudice the outcome because they know no one wants their loved ones to be in institutions and Linden Road is not an institution; it's a home/community residence for people with complex autism and learning disabilities and other needs where they can feel relaxed and peaceful and learn. It's not an institution it's their home from home.

💬 I believe that they would definitely keep things as they are now. I don't think people would be consistent. These people have very high support needs. Not many people would have to put up with some of the things we have to go to for the residents.

💬 Inconsistency - leads to change – and flips people.

💬 Agency workers don't care. Putting my hat on as an agency worker, they'd do 3 hrs max, leave and go back to agency.

💬 One resident was presented on paper as being the worst person ever. When he got here it was the complete opposite. The home he came from made him look a lot worse than what he was because we believe they wanted to get rid of him. Other homes under play or over play a situation so that they can rearrange a placement.

💬 Priority 2: The description on the paper that went to the Cabinet is saying that "Linden Road is moving to a better place in the community" and is putting a positive slant on it. Haringey Council fool the Councillors in to believing that they are making the right decision and that they are going to save money at the same time? So it looks like there is a win-win all round. It's all in the written language.

💬 Personal budgets pools resources and then continues the same thing. Maintain the current situation.



### 5.3 PROPOSAL THREE: Increasing the availability and flexibility of day opportunities within the borough meeting the individual need of residents.

#### Carers Focus Groups – Learning Disability (Ermine Road, Roundways, Birkbeck and Always Day Centres)

A joint Learning Disability Carers Focus Group was held for Ermine Road, Always, Birbeck and Roundways Day Centres and Linden Road. 17 Carers in total attended. The responses below are what ALL carers said about the proposed closures and changes to the day centres.

<b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.	<b>Question 1:</b> Do you support Haringey Council's proposal to close Roundways, Birbeck Road and Always Day Centres for adults with learning disabilities?	<b>Question 1 (sub question):</b> Please tell us why you feel this way?
	<b>Question 2:</b> Do you support Haringey Council's proposal to provide a new model of day opportunities from Ermine Road Day Centre through an alternative provider?	<b>Question 2 (sub question):</b> Please tell us why you feel this way?

#### Carer - Learning Disabilities



"Service users need a base to start their activities, some receive 5 day service and parent/carers know who is collecting them, where concerns can be raised and when they are coming home. Users are kept engaged and they enjoy coming and meeting their friends. Their personality is very different from being at home then when they are with their friends at the centre. You put them in the community, away from their friends and peers and behaviours will deteriorate, safeguarding concerns will escalate."

#### Do you support Haringey Council's proposal to close Roundways, Birbeck Road and Always Day Centres for adults with learning disabilities?

All 17 Carers **Strongly do not support**

- ☞ People with learning disabilities need stimulation and interaction with others. They enjoy coming to the day centres, they feel happy and that they have a chance to do something different each day.
- ☞ It's a time of fear for the family and for the individual who uses services. The provision of existing budgets does not mean that there will be sufficient funds for all the activities. The assessments are all about cutting cost.
- ☞ Fear of the unknown for carers and service users.



- 💬 We rely on these services as it gives us a break from the people we care for from the usual environment.
- 💬 What other provision are there?? The provided new models outweigh the existing model.
- 💬 Strongly against closures. Haringey seems to find the funds to do other works across the borough but they why have to close centres.
- 💬 My son is autistic – he is stable due to continuity. He gets that continuity through day centres. Consequences of these proposals will impact on my life.
- 💬 We value stability – the person I care for is not interested in flexibility but needs stability in order for him to function.
- 💬 Council already know how we feel, so why are you consulting with us again. I feel like we are going around in circles. I've taken part in many consultations and the end result is the council proceed with their proposals.
- 💬 We feel like a 'soft target' because there are a few of us who will fight but were getting tired and often feel what's the point as the council will do what they want.
- 💬 She can't go to the pub or café or socialise in the community as she believes that when food is laid out she thinks it for her. If I go shopping she will eat the food. If we pass a bin and she she's sees stale food she will grab it. I have to take it out of her hand very quickly.
- 💬 The council has given money to Tottenham football club – what about us?
- 💬 Fed up of attending these meetings when nobody listens. We ned to hear from the decision makers.
- 💬 Cultural and social care needs need to be met. She has no road sense; she cannot manage her personal care needs, she also has issues with female hygiene. Cutting out the day centre now and putting her in the community is not a good idea. They need to look into supporting her needs, not ignoring or rejecting her.
- 💬 Council has not offered alternatives??? Why haven't we got any concrete answers since the last consultation which was over 6 months ago? Other borough can function well – why can't Haringey?
- 💬 No information from Haringey. No one is taking responsibility.
- 💬 We pay council taxes but money is not going to LD adults.
- 💬 Why is Haringey so keen to go ahead with these proposals?
- 💬 We do not know what the alternative provider will provide and the quality of their service and the logistic of service delivery.
- 💬 We are getting a lot older – if sessions start at different times this will affect users.
- 💬 Loss of routine – people will be waiting around.

- 💬 The escorts/drivers are essential part and they make the person's day.
- 💬 Sister loves going to centre and talks about her day and her friends who are important to her when she returns home – this will be lost.
- 💬 Concerns raised around affordability and sustainability.
- 💬 Moves will affect behaviours.
- 💬 She needs the day centre to monitor her otherwise she would be in a very poor state of neglect. The day centre writes things in the communication book and no one looks at it until she comes to me on the weekend. Safeguarding concerns. It everybody's business.
- 💬 The day centre is imperative. It's not about the day centre is about new lease of life. Don't want her to revert. And I can't care for her myself I need to find long term care. I can't do

**Do you support Haringey Council's proposal to provide a new model of day opportunities from Ermine Road Day Centre through an alternative provider**

### Carer - Learning Disabilities



"We don't know what the questions means. We don't know who will be running. Could the external providers eventually charge us for the services? Why is there an external provider involved without making some sort of profit?"

- 💬 The day service is very good for my daughter. Anytime something happens to my daughter they have told me. She needs to be monitored and supervised. She can't even dress herself. The day centre staff know her well. Some know her up to 20 years and control her when she goes outside.
- 💬 I was a social worker until last year but had to resign due to physical ill health needs. So I know all about reviews, assessments and presenting cases to budget panels.
- 💬 Anti-social behaviour. Noisy, stuffing food in her mouth. Very few places accept people with disabilities like this. When she is distressed my daughter will bite her hand, slam doors, washing hands.
- 💬 I have fears. I'm alive and I don't like how they are treating her so my concerns are what will happen to her when I'm dead. Last year I took early retirement for health reasons.

- 💬 She suffered a lot and I'm trying to safeguard her. If I wasn't around to advocate for her she'd be in trouble. I've always got to be challenging people.
- 💬 Why couldn't you reduce services rather than nothing at all?
- 💬 They are placing a death sentence on my daughter's life.
- 💬 The external provider has to fund the services to certain quality and standard. What is the council going to do to monitor quality of service?
- 💬 There seems to be no accountability with the provider, what are the processes to go through?
- 💬 What happens when the provider doesn't have capacity to provide services.... Care quality report?
- 💬 Reducing services does that mean staffs lose their job? Will there be enough people to provide a good enough quality of service? What is the level of provision?
- 💬 Where are the decision makers – why don't they speak to us?
- 💬 There is an increase in agency staff who aren't qualified?
- 💬 People who made decisions now won't be there in place and it's our children who will suffer.
- 💬 In other places she has had a flea and urine infections. They cut off her hair because they couldn't be bothered to comb it and she had a severe scalp infection. There was also physical abuse and neglect in care. She had a punched arm and ended up in hospital.. They don't understand the type of food that she needs to provide.
- 💬 Why are we being told there is no money but council found 24 million to revive 'Ally Pally'?
- 💬 'Vanity Projects' like Hotspurs and Ally Pally but where is the money for us? WE Suffer.
- 💬 Quality assurance? Is there anything in place?
- 💬 Strongly do not support new model for Ermine Rd.
- 💬 How will the service be provided?? Will be difficult to find support for clients with will be costly space at Ermine Rd.
- 💬 The new model is likely to be costly for parent to afford and people who use the service may be deprived from having access to good facilities.
- 💬 Concerned about adequate staffing from new provider, they will not know my son/daughter.
- 💬 This community proposal doesn't work for my daughter. I don't think that certain professionals and providers understand enough about the needs of learning disabilities and people with autism. She needs a comprehensive assessment. Her care and support needs to reflect her needs and should not be budget led.
- 💬 Impact on service users behaviours – feeding of peer groups and vibes around.

- 💬 Impact on service users – changes relating to buildings, staffing etc.
- 💬 Not all have capacity to make choices relating to changes.
- 💬 S/U do not like changes.
- 💬 If people want to buy their own services what's the real cost?

### Carer - Learning Disabilities



If these cuts are going ahead why are the council not up front about it? What are the alternatives? Council using subtle discipline language – I find it very insulting. Everybody in residential and attending day centre will get a review of their needs. Day centres have 148 people – are you expecting to find these 148 people's needs have fallen?

- 💬 My brother cannot use public transport he is totally dependent on carers.
- 💬 I am absolutely livid and fed up. They keep telling us they know what they are going to do already. Is it worth us going through this process?
- 💬 Parent and member of SASH. We know we have to consult.
- 💬 Dramatic effect on families – people trapped in their own homes, socially isolated, depression, emotional turmoil.
- 💬 Money is spent elsewhere.
- 💬 Important that those with severe autism need continuity.
- 💬 Consequences are to be back at home.
- 💬 Haringey has not said what community activities are?
- 💬 The structure supports the person's behaviours.
- 💬 Stability not flexibility – does not work for all.
- 💬 No response to letters sent to the council
- 💬 The council say they care but they don't, we're seen as a soft target
- 💬 What does community opportunities mean?

- 💬 Would we have to change of personnel
- 💬 Keeping the personnel the same is crucial to service delivery
- 💬 An alternative provider could be unstable
- 💬 Private provider contract length is detrimental – not responsive
- 💬 No accountability – how do we air our grievances
- 💬 Quality assurances
- 💬 We do not know who the private provider will be
- 💬 Some services got a rotten CQC – Haringey failed to properly regulate
- 💬 Haringey is buck passing the responsibility
- 💬 Will there be staff cuts? – reducing facilities means losing qualified staff
- 💬 Temporary staff (agencies) not properly qualified
- 💬 Not speaking to anyone who can change the decision
- 💬 Being asked about a ‘leap in the dark’
- 💬 Haringey don’t know where they’re going or are they hiding what they know
- 💬 What is meant by care
- 💬 People who are responsible will be gone in 5 years – then the cycle starts again
- 💬 How the council can chose ‘vanity’ projects over our loved ones?
- 💬 Parents will want assurances that assessed needs will continue to be met fully and there is no deterioration.
- 💬 What are the alternatives?
- 💬 What are the time scales for carer’s assessments? AW stated there will be some prioritising.
- 💬 Qualification of staff.
- 💬 Can you prove it will be cheaper?
- 💬 We need to know what the new model will look like.
- 💬 Users will miss their friends.
- 💬 We feel people do not care and don’t listen to us.
- 💬 My daughter looks forward to coming to the centre.

- 💬 Why do they let go of good staff.
- 💬 We need to bear in mind no matter how severe the individual is – they do enjoy the activities and need to be around good caring staff who are able to monitor them.
- 💬 We need more information to make informed choices.
- 💬 Support from council a bit hit and miss. Feel service would deteriorate further.
- 💬 Will there be an open tendering process to provide services?
- 💬 Question is misleading. A new service from Ermine Road. The new model involves personal budgets and anyone in residential care and supported living etc. will not receive a Personal Budgets. Only those who live with their families. How will they be assessed?
- 💬 Those living in supported living, what will they do if they are not able to access their services.
- 💬 What's the hidden agenda?

## Service User Workshops 1 and 2 – Ermine Road Day Centre (Service Users and Circles of Support – Carers and Staff)

<b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.  (Objects of Reference and Pictures were used to support understanding of the questions)	<b>Question 1:</b> Do you support Haringey Council's proposal to make changes to your day services?
	<b>Question 2:</b> What activities do you currently enjoy/do at the centre or in the local community with support?
	<b>Question 3:</b> Who helps to support you at the Ermine Road?
	<b>Question 4:</b> If you had your own money (a personal budget) to buy services or activities would you choose to: 1) Continue buying a service like what the Ermine Road offer? 2) Would they choose something different? (Alternative care) 3) Or would they mix it up? (a bit of the old and something new?)

### Service User - Learning Disabilities



Service users need a base to start their activities, some receive 5 day service and parent/carers know who is collecting them, where concerns can be raised and when they are coming home. Users are kept engaged and they enjoy coming and meeting their friends. Their personality is very different from being at home then when they are with their friends at the centre. You put them in the community, away from their friends and peers and behaviours will deteriorate, safeguarding concerns will escalate.

**Workshop 1 – 8 Service Users, 1 Carers and 7 Staff.**

**Workshop 2 – 6 Service Users, 2 Carers and 5 Staff**

**Do you support Haringey Council's proposal to make changes to your day services?**

13 Service Users **Strongly do not support** proposals to make changes to their day services.

1 Service User supports the proposal.

**What activities do you currently enjoy/do at the centre or in the local community with support?**

- ☞ Singing and dancing, aromatherapy, beauty sessions
- ☞ Art.
- ☞ Music sessions, MATP – Motor Activity Training Programme, Hand eye coordination, manual dexterity, frequency, relaxation. Bingo. Gardening.
- ☞ Artscape – Art sessions
- ☞ Movie time – pull the blinds down, popcorn, chose the movie.
- ☞ Cooking
- ☞ Small group does travel training.
- ☞ Rebound therapy – Physiotherapist and senior staff members, Speech and Language Therapist involved. 6 week cycle of support with 4/5 different service users. Benefit – people in wheelchairs gentle exercise, circulation. There is nothing similar anywhere else.
- ☞ MATP – Motor Activity Training Programme, eye hand coordination. People in wheelchair passing ball, parachute, reflex.
- ☞ Zumba – Every Tuesday pm.
- ☞ Tibetan bowls, aromatherapy, mild yoga, sensory relaxation, meditation, spiritual. Ambience, Incense, music, relaxed. Internal staff trained in this.
- ☞ Cycling
- ☞ Swimming
- ☞ Hydrotherapy
- ☞ Rebound therapy in the gym
- ☞ Accepted for who she is
- ☞ Match faces to famous people
- ☞ Meet and greet people
- ☞ Sit in the reception area
- ☞ Likes different faces
- ☞ Interaction
- ☞ Socialising
- ☞ Shopping
- ☞ Prefer 1-2-1

**Who helps to support you at the Ermine Road?**

- ☞ Showed us the staff do. Pointed to the staff.
- ☞ Pointed to a particular member of staff.
- ☞ Escorts - familiar people are very important

- ☞ Staff are very skilled. Fully trained. Aware of service user needs. Giving the staff the support to do their job properly.
- ☞ Service users support each other.
- ☞ Drivers
- ☞ Support workers
- ☞ Friends
- ☞ Also things like the bus itself.
- ☞ Held staff members hand.
- ☞ 2 Service Users are friends with a staff member – support (Bus – who they like to sit next to).
- ☞ 1 service user is attached to a member of staff. He makes a noise
- ☞ She has autism and learning disabilities. Bus coming – looking for familiarity. Key worker. People who she knows. She has likes and dislikes.

### Service User - Learning Disabilities



“She is aware at some point Ermine Road will close/change. She understands. She gets very upset. Starts crying. Everyone who works with her service have been with her for a long time. She looks for the staff she knows. She lives with one lady. Where she lives – just her and her carer. She has one sister. Friends have been asking her to start swimming. She travels independently on learnt routes to see her sister. She could be psychologically affected/damaged. If any of these services were taken away. She is physically able.”

- ☞ He would find it very difficult if he lost his keyworker. He is a man of routine, he likes familiarity. I've heard from staff when I am on A/L he is a different person, he is reserved and does not enjoy the day as much.
- ☞ When he is at home he does not leave the home. When we go out we do exercise. At his home they find it very difficult.
- ☞ She recently had a change of residential home. She is very reserved. She stopped eating and didn't respond to anyone. She was at Whitehall Street but moved separately from everyone else. She was on her own. Her needs were different. Took a long time for her to settle. She shut down.
- ☞ Very sociable and wants to do more. She needs time to understand and adapt to change. Portuguese background. Support worker understands Portuguese. She is able to understand me. She likes activities and to do things. She would need time to adapt.
- ☞ Gestured - sad, cry. Patted her hand waving goodbye to the staff – would be sad. She has her routine very much in place if there is a change at home for example mum not there she will sit on the floor, totally refuse to move.
- ☞ Important that she has people that she knows – she has likes/dislikes. Familiarity. Familiar staff here. She was very ill. It set her back 10-15 years – in terms of independence, walking and talking. Everything relearnt. Does not deal with change very well. Her 'work' is going to the day centre. She calls the day centre work.



- 💬 Gardening is done by a member of staff and service users. We won an award 'Haringey in Bloom'. Unbelievably beautiful. Service user involvement was very little but sessions could be adapted with the right support.. There are service users who access the garden.

**If you had your own money (a personal budget) to buy services or activities would you choose to:**

- 1) Continue buying a service like what the Ermine Road offer?
- 2) Would they choose something different? (Alternative care)
- 3) Or would they mix it up? (a bit of the old and something new?)



### Service User - Learning Disabilities

"Service User (non-verbal) does not like change he becomes very anxious. He self-harms. He may start to hurt himself. When he becomes anxious he can become violent to other people. He does not respond well to new people."

- 💬 I want to come back to Ermine Road.
- 💬 I would buy drinks. Loves going out.
- 💬 I would buy into it to go out on the bus.
- 💬 Social life – I would buy different activities, travel, and holidays. Would like to be out and about more. Needs a cultural connection/religion.
- 💬 (Staff on behalf of service user) The wider community does not like us. We feel like we have our own community here. The wider community is not good at socialising. No facial expressions- we do not know how to meet and greet. Do not feel comfortable. Some places do not make us feel welcome.
- 💬 Most of the staff I have known for years. (Staff on behalf of service user) but she is over familiar with strangers she would go off very easily.
- 💬 (Sister on behalf of service user) This place is flexible if she is not going on a particular day or there is a service user who she does not get on with she can come on a different day. She has choices.
- 💬 Service User began shouting and became abusive. She will not engage. Refuses to join in.
- 💬 She would be charged if she employed a PA – had her own budget.
- 💬 When needs were changed staff at the day centre recognised deterioration in condition and personality. Her medication has now been changed and now reversing the effects.
- 💬 Day Centre – Community.
- 💬 Where else can you go and have a spectrum of different people who make different noises/sounds? Different personalities. Can they fit those into the wider community?
- 💬 Judged, not accepted?
- 💬 Nowhere else to go people would not accept them.
- 💬 This seems to be an efficient way of providing a wide range of services.

- 💬 Challenge the people making the decisions to come to the community services and participate and listen to all the vocals/sounds to see how this could not work in the wider community.
- 💬 This will encourage institutionalisation. Some people will be scared of the wider community they may lock their loved ones away.

## Service User Workshops 1 and 2 – Ermine Road Day Centre (Circles of Support – Carers and Staff)

### General Comments

- 💬 I do not believe that LDX can be independent other members of staff should be doing this.
- 💬 All round general feeling of frustration like most of us. What will be the future of the service and service users? Every day we have to deal with this. People are crying.
- 💬 Ermine Road needs to change. The process is wrong.
- 💬 We've been going for months.
- 💬 No regard for service users.
- 💬 Quality down
- 💬 Frustration
- 💬 Morale is low.
- 💬 Some service users do not understand and never will. That is where the impact is.
- 💬 Creating a space for service users and carers to be listened to nothing for staff!
- 💬 This here is not new. We are expecting the worse.
- 💬 Complex health, community hub and autistic spectrum are based at Ermine Road.
- 💬 Trained staff using and passing on skills should work with existing staff and service users to make better Ermine Road. Not enough resources and activities.
- 💬 Training is open here you can go to the managers and they will try to help you to access that.
- 💬 Who will notice change if something goes wrong?
- 💬 Staff – go above and beyond take people to get new jacket, to the barbers to health appointments. Buy clothes for service users. For example support worker was asked by social worker to buy clothes for a service user as parents could not do this.
- 💬 We do this because we care...
- 💬 People will get seriously hurt.
- 💬 One particular gentleman 50+, it has taken years to build a relationship with him and for him to meet others would be very, very hard. It would affect his health and wellbeing.
- 💬 For some people this is life or death.
- 💬 There will definitely be failings. Safeguarding issues.
- 💬 Shorten life expectancy.
- 💬 Increase stresses.
- 💬 Depression, withdrawn, sad.
- 💬 Behaviours will deteriorate
- 💬 We have worked with these service users for years. We know what works well. If transition is managed not well it will be disastrous.
- 💬 Will they be medication wise?
- 💬 Service users will become reclusive
- 💬 May not know anyone if new staff. May not be able to spend time with experienced staff members.
- 💬 Parents and carers trust us.

- Who will check in and attend reviews individual with me for 5/6 hours per day I notice changes.
- Residential homes - how will they cope? Some homes send service user in with the wrong equipment and the communication books are not being read.
- No consistency with bank staff.
- Here is basically home because their homes are the extension of here. But there is no consistency. It is not home to them.
- Increase vulnerability. Exposed
- Health related concerns.
- Emotional and Psychological issues.
- It takes a very long time for individuals to build trust.
- Depends on who is providing the service?
- People will have the opportunity to have personal budgets – opens up physical and financial abuse. There is no monitoring in place.

## Service User Workshops 1 and 2 – The Roundways Day Centre (Circles of Support – Carers and Staff)

<b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.  (Objects of Reference and Pictures were used to support understanding of the questions)	<b>Question 1:</b> Do you support the closure of the day centre?
	<b>Question 2:</b> What activities do the service users currently enjoy/do at the centre or in the local community with support?
	<b>Question 3:</b> Who helps to support service users at the Roundways?
	<b>Question 4:</b> If the service users had their own money to spend on care services (a personal budget) would they choose to: <b>1)</b> Continue buying a service like what the Roundways offer? <b>2)</b> Would they choose something different? (Alternative care) <b>3)</b> Or would they mix it up? (a bit of the old and something new?)

### Carer – The Roundway



“My daughter is an opportunist. She would take advantage of staff she did not know. She is used to staff here. They know her and can control her. She will sit in the middle of the road. You have to work on instinct. Safety is important. You have to be two steps ahead of them. It takes years and years to get to know her. If that member of staff hadn’t known her and been quick, she would be off in the road.”

## Workshop 1 – 10 Carers and 7 Staff.

## Workshop 2 – 3 Carers, 2 Staff and 1 Councillor

### Do you support the closure of the day centre?

13 people **Strongly do not support** the closer of the Roundway.

- Very secure here – they stick to the programme.
- The Roundway is small – only day centre for autistic in Haringey
- NAS - Need a safe environment plus predictability with highly trained staff. Breaks in routine results in challenges.
- Service User would be lost if Roundway goes
- Not everyone can access the community without high ratio of staff or use public transport.
- The team work together.
- Difficult if 1-1 so public transport is not adequate to provide the right staff.
- Don't think most staff would work 1-1 – possible dangers in public?
- Had many moves in the last twenty years – move from Keston to the Roundway
- We were told that the Roundway is permanent?
- Lack of sleep, impact on carers. similar experience for all
- Regarding the move from Keston - we were told Roundways was the best place by Haringey Social Care Team.
- NAS – said this would happen and stressed must be in place with answers.
- Challenges increasing. One service user attacked mum's granddaughter.
- Service users are anxious and behaviours changing – sleep patterns has a big impact on their day.
- Need to do changes very gradually.
- They need time to process the information.
- When there is a change in route e.g. they will even try to get out of a moving vehicle.
- You don't know how everything could cause chaos.
- The emphasis is on trust, what keeps them safe.
- One user has become aggressive and agitated saying that he doesn't want the day centre to close.
- The hardest thing is we cannot give them answers plus service users cannot put it into concept.
- In a few year's time all the staff will be gone.
- Very secure here.
- Programme stick to the programme.
- Small. Suits needs.
- Rightly trained in Autism and Challenging behaviour.
- Expert staff will be lost.
- Not all the attendees can attend the community.
- Even if the condition is understood it is being ignored. Complete ignorance.
- The spectrum is not understood. It is taken for granted.
- They rely on routine and things they can predict and control. Being in a world that is predictable to them. They just want to live. They are being put in a position.
- Impact on me and on my whole family because of the move and current housing accommodation. The distance to travel to the service especially if it is at Ermine Road. We move out of the catchment area which will put pressure on me. I'm struggling to maintain this. Because of moving I don't get what I did get before for him. I need to get a life. It is a clash to pick up my daughter and son.
- Tried to find a personal assistant but could not find one.
- Going in a taxi would be too expensive.
- If I could get a personal assistant it would help greatly.



## Carer – The Roundway

“For 22 years living in one community he has built up is independence. Now I have moved he does not have those community activities. The activities are the main thing and take the pressure off for the family. My son can adjust and accepts a lot. I now rely on Roundways for activities. It’s about timescales for me.”

- 💬 Residential staff – my client has been coming here for 15 years. It is her routine and would be disruptive.
- 💬 This place is a community and he belongs here and that would be taken away from him.
- 💬 Move him to centre 2 years ago. It took a long time for him to get used to the Roundways and now service users are starting to trust staff. E.g. service users did not want to come to service but built up trust and now he comes.
- 💬 He will start displaying challenging behaviour at home.

### Why – do not support?

- 💬 Residential staff – he does not like the change and would be a problem. Current staff he knows them. He knows the routine; bus journey etc. his mother says “my son does not want the change”
- 💬 Residential staff – it will not be easy and we won’t be able to provide enough activities in a residential home. What more can we do? There will be a big gap.
- 💬 Residential staff – The change will result in more behaviour. It will affect them as it will take time to adjust.
- 💬 Residential staff – More continuity and breaking consistency plus it will have an impact on his routine and coming out the house. Groups sessions we can provide this.

### What activities do you currently enjoy/do at the Roundways or in the local community with support?

- 💬 Lots of activities including: Swimming, cycling, nature walks, cooking, gym, painting, Zumba, sewing (see also Autism Spectrum Programme given).
- 💬 If you break the routine it will make them angry. It has a bigger impact if routine is broken.
- 💬 You have to really know them to take them out.
- 💬 Activities are more tailored.
- 💬 Some that can go into the community need high staff ratio. How do they access public transport?
- 💬 In Haringey their reliance on formal methods of care. You cannot do that with people with autism. They cannot communicate.
- 💬 My daughter refuses to go on public transport. Yells and screams. Could not get her on the bus.
- 💬 Trampoline, pedal power, swimming, church, Epping forest.
- 💬 The programme is tailored to each person.
- 💬 It is very varied and different everyday – people choose what they do.

- 💬 Most activities are outside.
- 💬 Bad weather keeps them at the Roundways. Winter and summer programme.
- 💬 If Roundways wasn't there – they come together as a group, meet their friendships and socialise and know each other for a long time.
- 💬 Residential staff – we take them to Mencap dance. If they were at home they would be bored.
- 💬 They can pool personal budgets to meet up and socialise. Residential services shouldn't do support for those families.

#### 💬 **Who helps to support you at the Roundways?**

- 💬 Staff, escorts and drivers.
- 💬 Drivers come to home and pick them up
- 💬 Staff have training
- 💬 Everyone participates in joint review meetings.
- 💬 Trust, relationships, we know them very well – staff, drivers, escorts – all very well trained qualified and know how to deal with people.
- 💬 Well trained staff. They are used to the staff.
- 💬 Staff know what they do before they do it.
- 💬 She knows friends and staff.
- 💬 People see her and say what she has done is bad. How could they know her?
- 💬 Do not like changes even personal assistance at the house – new staff are not welcome. Even new ones she will look at and say no. she would not allow them to touch.
- 💬 Formed relationships and trust.
- 💬 If carers having difficulty staff at Roundways will help to get things done.
- 💬 There are things that service users will not do at home but staff can get them to do at Roundways.
- 💬 Emphasis on its later years.
- 💬 Doing things at centre that enable people to deal with day to day issues. E.g. one user slanting to say words.

### **Carer – The Roundway**



“For 22 years living in one community he has built up is independence. Now I have moved he does not have those community activities. The activities are the main thing and take the pressure off for the family. My son can adjust and accepts a lot. I now rely on Roundways for activities. It's about timescales for me.”

- 💬 Staff are able to calm service users down and give us peace at home. They are more than members of staff. So they can try a different approach.
- 💬 Residential staff – my client does not want change and listens to the keyworker because they've been together a long time.
- 💬 Closure is not in the best interest of the clients.
- 💬 NAS – Council meeting in February 2015 – Head of Adults Social Care and Cllr Morton recognised

- 🗨 that this is the most vulnerable group.
- 🗨 It's being undervalued.
- 🗨 Paying money out on a lease. Wasting money on the lease. The council is tied up Bounds Green and Always.
- 🗨 NAS – Ermine Road is not safe – they were moved from there in the first place because of safety issues. So many fire doors which are not locked so people will abscond. What does being safe mean?
- 🗨 E.g. only place – Roundways she has not run away from.
- 🗨 Staff – the autism spectrum not understand. They only rely on feelings and things they can predict. Service users are being put in a position which is being taken away.
- 🗨 If it is not being understood and being ignored.
- 🗨 NAS – the core of the disability has to be taken in to account - ignoring their human rights. Carers did have a good will of those around them but that is finishing.
- 🗨 Transport is a massive issue. If there is no transport it would be mini cabs as most service users are unable to use public transport.
- 🗨 The impact on the wider community because of behaviours – e.g. use of public transport or only get on one bus route.
- 🗨 It feels like we are going backwards.
- 🗨 3 years – 30 years 11 years – a lot of staff have known service users since being a child.
- 🗨 Residential Staff -
- 🗨 Need stability, trust of staff.
- 🗨 Generally do not like agency staff
- 🗨 It takes weeks and weeks just to prepare a service user for an outing.
- 🗨 Not able to change bus routes etc. every day that we take for granted.
- 🗨 It has taken years to build relationships with between staff and users.
- 🗨 This has a high impact not just for us but on the wider community

**If the service users had their own money to spend on care services (a personal budget) would they choose to:**

- 1) Continue buying a service like what the Roundways offer?
  - 2) Would they choose something different? (Alternative care)
  - 3) Or would they mix it up? (a bit of the old and something new?)
- 🗨 It would have to be like this – because they are safe and happy. Staff understands them and it takes years. Bruised service user relationships but it will not appear so until someone is not there.
  - 🗨 I am happy with the way things are.
  - 🗨 What are the alternatives with personal budgets? What can we buy?
  - 🗨 NAS – we do not know what alternatives there are?
  - 🗨 What about those parents who work?
  - 🗨 Both parents working. We go beyond. We start earlier so we can pick up son.
  - 🗨 e.g. one person had a personal budget and it ran out in a few months.
  - 🗨 Once the money is gone it's gone.
  - 🗨 Are those doing the reassessments – are they autism trained? Massive cost implications because of autism.
  - 🗨 Assessment forms are very generic and misrepresent because autism etc.
  - 🗨 Assessment should be simplistic not complex. Not asking the right questions
  - 🗨 Less day service – might commit suicide?
  - 🗨 I would end up committing suicide.
  - 🗨 I would crack up.
  - 🗨 People carry out the assessment do not understand autism – they take answers on face value rather than digging deeper.
  - 🗨 They will be asking questions that the service users cannot answer.



- 💬 They (service users) can do a lot of things but not in the right way.
- 💬 Autism is for life. They need support to enhance skills. Needs do not change. Disability does not change.
- 💬 The financial assessment no one here trusts.
- 💬 NAS – We know Haringey personal budgets team are asked to cut budgets. Every year staff in social services and the council are the decision makers and the decisions change.
- 💬 We need a definite answer to what is being put in place and how long it will take.
- 💬 Default of the long term transition.
- 💬 Have Haringey council started to talk to all residential and how are they being consulted?
- 💬 One carer said that residential are only funded when she is there e.g. mum every day and weekends.

### Carer – The Roundway



“He is a strong man who would slam doors, slapping himself and screaming. It will be chaotic. We will have to employ more people. It will take time for people to get used to new staff. Given the option 2-3 years ago for personal budgets. Many did not want a personal budget. They saw it as an extra responsibility – they wanted what they have at the Roundways. Service user is happy with the service.”

- 💬 What is the process in place after this? Who will be involved in the decision making? They need to use experts in autism e.g. NAS
- 💬 NAS – wants to recommend that consultant with staff in the planning process, transition and the future.
- 💬 Will they take notice of what we are saying?
- 💬 We as carers are getting older and hoped that our loved ones will be staffed. All our hard work has been jeopardised by the cuts.
- 💬 No respite which affects me having my daughter at home.
- 💬 We have to brief them. How will they understand that it will close?
- 💬 A reduction they will accept.
- 💬 A comprehensive transition is needed.
- 💬 Staff need to be appropriately trained to take over the services.
- 💬 Change in behaviours.
- 💬 It takes time to process information.
- 💬 Impact on behaviour and they will struggle in the beginning.
- 💬 Residential staff – It could have impact on other residents.
- 💬 Residential staff – We also have people with mental health issues who might have a break down.
- 💬 Residential staff – Because of length of time coming here it will have a big impact. E.g. one person self-harms.



## Service User Workshops 1 – Always and Birbeck Day Centres (Service Users and Circles of Support – Carers and Staff)

<b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.  (Objects of Reference and Pictures were used to support understanding of the questions)	<b>Question 1:</b> Do you support the closure of the day centre?
	<b>Question 2:</b> What activities do you currently enjoy/do at the centre or in the local community with support?
	<b>Question 3:</b> Who helps to support you at the Roundways?
	<b>Question 4:</b> If you had your own money (a personal budget) to buy services or activities would you choose to: 1) Continue buying a service like what the day centres offer? 2) Would you choose something different? (Alternative care) 3) Or would you mix it up? (a bit of the old and something new?)

### Circle of Support – Always and Birbeck Day Centres



“People will be isolated on individual budgets, we have users here who are very vulnerable and this will lead to being taken advantage of. Some struggle to raise their voice. Change is good for us we can cope with this but for our users they find changes difficult to cope with. It will be a big struggle and will affect those who support the users but also their immediate families.”

### Workshop 1 – 17 Service Users, 2 Carers and 5 Staff

#### Do you support the closure of the day centre?

17 Service Users and 2 Carers **Strongly do not support** the closure of Always and Birbeck

- 💬 The council are thinking of closing this centre?, !!!!
- 💬 How do you feel if they did this – All of the group said they would feel sad, upset, angry, cry, not happy
- 💬 Service User gave a letter saying why she does not want the centre to close.
- 💬 We do not want it to happen, we will get our banners and tell them to keep it open. One individual started to cry, another started to cry,
- 💬 I person wants Always to close and keep Birbeck open.

### What activities do you currently enjoy/do at the centre or in the local community with support?

- ☞ Service users use the mini bus for centre, public transport or come to the day centre on the mini bus.
- ☞ The centre has a 16 week programme which users are involved in planning. When they come to the centre they have drink, see what activities they have and at times change activities. There is summer and winter programme.
- ☞ Cooking – I do cooking and a support worker from the centre takes me from home and return. One to one to drop and pick up. Staff who do this are from the centre,
- ☞ Musical activities - music therapy on Monday
- ☞ 13 people like Art. We do it here.
- ☞ 8 people like computers. We play games, we have iPads.
- ☞ All of the service users like listening to music. Elvis, Cliff Richards, Elton John, Five Star, Country and Western, Classical and pop music.
- ☞ 7 people like beauty, makeup and painting their nails
- ☞ Outdoor activities include bowling, cinema, going out, football and cricket.
- ☞ People find watching TV boring. They want to be at the day centre.

### Who helps to support you at the Roundways?

- ☞ 1 service user lives on their own with support.
- ☞ 10 people live with their families.
- ☞ 5 people live with other people.
- ☞ 10 people have their own keys to their home.
- ☞ 10 people need help with personal care and 5 people do not.
- ☞ Staff at the day centre help us.
- ☞ Do you go to each for help –
- ☞ We talk to each other and help each other,
- ☞ We have friends here and look forward to seeing people,
- ☞ Our carers support help us get ready - pays for activities - we give the money to keyworkers to pay for the trips,
- ☞ Bus drivers and escorts to brings us here,
- ☞ Who helps you with the meals - we bring lunch but staff support us to heat up food in the microwave. some go out to buy lunch

### How would you feel if different people supported you?

- ☞ Upset.
- ☞ Sad.
- ☞ Wouldn't trust them.
- ☞ Might not like them.
- ☞ Wouldn't know us.
- ☞ Wouldn't know the person.
- ☞ We wouldn't see the people who know us the best.
- ☞ We would miss our keyworkers.
- ☞ Safety.
- ☞ Centre and staff make sure we are safe.
- ☞ New people will not know us. It is important that we get to know new people.



## Circle of Support – Always and Birbeck Day Centres

“People will be isolated on individual budgets, we have user here who are very vulnerable and this will lead to being taken advantage of. Some struggle to raise their voice. Change is good for us we can cope with this but for our users they find changes difficult cope with. It will be a big struggle and will affect those who support the users but also their immediate families.”

**If you had your own money (a personal budget) to buy services or activities would you choose to:**

- 1) Continue buying a service like what the day centres offer?
- 2) Would you choose something different? (Alternative care)
- 3) Or would you mix it up? (a bit of the old and something new?)

Service User 1 – I would save it. I don't like to spend it.

Service User 2 – I would buy different services.

3 Service Users – It all depends of types of activities the other person was offering. So we would mix it.

11 Service Users would spend their personal budget to come to the day centre.

2 Carers would support their loved ones to spend their money at the day centre.

## Service User Workshop 2 – Always and Birbeck Centre (Circles of Support – Carers and Staff)

**Workshop 2 – 8 Carer, 2 Residential Staff (Paid Carers) and 1 Councillor**

7 Carers **Strongly do not support** the closure of the day centres.

1 Carer **Strongly supports** the closure of the day centres. (Residential staff)

2 Carers chose to remain **Neutral**

### General Comments

Discussion was had about the various moves the users have had from Keston Centre and then Always and Birbeck. **We all strongly feel it should not be closed.**

As for personal budget I would never agree to that, as most of our children are not able to manage money and I don't have the capacity to do it.

I strongly support the closures. When we look at social care history all these people used to live in care homes, they have to make choices and decision, grouping and stigmatism, I believe if the council can do the assessment right and not all individuals have the same care needs, we have to look at the funding as some are double funded.

- ☞ People are group together and stigmatised, these types of day centres and people are being grouped together and not all have the same needs and not being individual. Not all are able to express choices, and some are not able to say, some are double funded and some are using services in both places.
- ☞ I would like to remain neutral because the day centre is a good provision and service users enjoy coming. I don't have enough information so I am unable to make informed decision. I would need a lot more information on services and also what the assessment will be. I do recognise the good provision of day centres, also it would be good to have a list of other service to enable us to view which would be best for our cared for.
- ☞ My daughter lives at home and previous history was like home from home, no longer service users, they are now clients this feels very cold. Staff are no longer being replaced when vacancy occurs so where will they get the money to give us personal budget?
- ☞ The centre knows them as individuals; the community does not support our users, and does not understand. There is no care, no heart and no money.
- ☞ Double funded. When retracted we have to find alternative activities, our service users most of them have autistic traits and find it destabilising. Unable to cope with change, this gives them the opportunity to mix with their peers. The current service gives them structure, routine and a sense of purpose.
- ☞ People look forward to coming to the centre - why do they want to close it, if it's financial why do they target the vulnerable and how it impacts on vulnerable and the risk it puts on everyone.
- ☞ What are the alternatives?
- ☞ Those who attend here, they are always talking about what they have done, what they are going to do and what they have now they look forwards to activities and seeing their friends. They also talk about the staff and in way giving them social interaction and stimulating them with their friends.
- ☞ Why do they have to close, it really upset them, it gets them confused. It gets them anxious and agitated about what changes are going to happen.

### Circle of Support – Always and Birbeck Day Centres



"It's about focus. It gets people out into the community, everyday life, socialising activities, such as going out with group of friends, gardening, bowling, cooking, sightseeing, galleries, parks, dancing, Monday club, Makaton, snooker, planned explorer groups, swimming etc.. When staff changes they are not replaced and then activities stop. They do music and sing in a choir too."

- ☞ People who support include family members, homes, supported living scheme, escorts and bus drivers. Those in care also use public transport and dial a ride. The staff, users are always talking about them. Also it complements our residential services as we are able to converse with the staff on array of issues and this helps with smooth service delivery to our user.
- ☞ Those who are in residential the cost would be more expensive for the supporting organisation when out of day centre. If not eligible for services then the impact will be extra staff will be needed to support individual with activities, social interaction and health and wellbeing.
- ☞ When the others go to the day centre one individual has lots of support and we are able to get her out. The structure will be broken which will unsettle all service users. This will have a huge impact on the whole of the household. They are able to socially interact and have friends. With no additional funding we will not be able to fund extra staff. The impact will not be good.

### Circle of Support – Always and Birbeck Day Centres



“There is not a lot out in the community. Many services have closed down as there is no funding. Most people will be at home. People will not hesitate to come to the day centre but if you talk about going for activities they would refuse. They have relationship and friendship groups and get up eagerly for it. They will be exposed to financial exploitation, such as agreeing to things, paying for service which service users do not want etc.”

- ☞ The group holidays have now stopped and she misses it terribly. All these things they used to do, lack of staff and we used to pay for it. Carers would subsidise to pay for additional activities, these were only for those living at home, and we paid for these ourselves, there is no respite care break.
- ☞ It will be devastated for my daughter; she looks forward to coming even when ill.
- ☞ We can't imagine what her life would be like without it. I am getting older and if it's taken away I will die caring for her.
- ☞ She will be isolated and has been coming to the Council Services for the past 43 years and I can't do things she wants to do. She looks forward to going and seeing her friends.
- ☞ It would impact on our residential service because our users health and wellbeing will be effected. Their social skill will be limited to those living with them and this is not good for anyone. Social isolation – They will not readily want to do activities with those they live with and choices would be limited. If users do not want to engage then this would have an impact on the whole of the home.
- ☞ This will be taking away their rights of users as this will be taking away the right to community and peer support that will not be available.
- ☞ There is no extra staff during the day time, the impact on the user is that they will become aggressive, depressed and challenging.

- 💬 He would not understand changes and will display aggression. The bottom line is they do not like change.
- 💬 There should not be any segregation but that's not the reality. Disabled people are treated badly.
- 💬 I worry more about him, I class myself as his mother. He would not tell me if he is sick as I would stop him from coming. He loves it here.
- 💬 My daughter loves coming here.
- 💬 Our responsibilities will increase, we would need more support, when users come here the home have no staff and this would be a financial pressure.
- 💬 It would be interested to see a program of activities and the logistics of how this is delivered, would it be cheaper?
- 💬 There is not much out there. They will be socially isolated - no friends.
- 💬 I don't think it will ever work

If you had your own money (a personal budget) to buy services or activities would you choose to:

- 1) Continue buying a service like what the day centres offer?
- 2) Would you choose something different? (Alternative care)
- 3) Or would you mix it up? (a bit of the old and something new?)

- 💬 8 said they would spend it on the day centre.
- 💬 1 person said they would support the service user to purchase something different.
- 💬 1 person said they would support the service users to purchase a mix and would be interested in looking at different things.
- 💬 They would choose to come here, it's routine and they know what they are doing. They are happy and find changes difficult.
- 💬 A lot of our service users would need of support to make these decisions. We are taking away a lot of what people are used to. They can't make choices, their social position is limited. Recently we have had clients turned away from services/activities as they don't fit the remit. We don't think that the services out there are equipped to handle our service users.
- 💬 Are they going to get a personal budget, and is it going to happen? The individual's choice and views are over ridden by family. I have serious concerns about safeguarding e.g. Control by others.
- 💬 People's views and behaviours can change after services change.
- 💬 We think we could be going back to the days of institution, whereby isolated at home.
- 💬 5 years since Keston, then we went to Always, now Birbeck. No one is taking account of the human elements.
- 💬 I hope it stays.

- 💬 It's been really interesting for councillors hearing views, I hope there will be improvements and the centre stays open, they should look at the individual and perhaps take the human approach.
- 💬 The service has been a security in my loved ones lives and I think changing and closing will bring challenging behaviours by the individual
- 💬 I have a vested interest and I think it is absolutely vital for the service to remain open within the budget constraint; we strive to improve and ensure appropriate staff is in place. Safeguarding - systems in place, list of activities should be made available in resource centres.
- 💬 I hope it stays, she thoroughly enjoys coming. Please reconsider and find something else to close.
- 💬 This is a part of their lives.
- 💬 I think this should stay; my main worry is safeguarding and associated risks. How this will impact on individuals in terms of behaviours. Staff ratio will need to increase but this is not funded. Everyone is at risk.
- 💬 Our house will be full of people, there are times when service users do not want to be with the person they live with 24/7. Some challenges will happen. Peer abuse, sexual abuse, physical abuse.
- 💬 The centre reports any concerns asap. From a minor scratch, to changes in behaviours etc. People don't have a choice where they live.
- 💬 If they are living 24/7 in home then abuse can be covered up but a combination of services will raise alert. Staff here has a strong bond with individual users and are at ease to disclose concerns.
- 💬 We should be able to move forward as changes can be seen as positive and individual assessment will bring out the need. Not everything fits for all. We need to embrace services changes.
- 💬 Who will do the review when some haven't been done for 18/24months based on past and present experience when they are struggling right now?
- 💬 The whole package takes time; the social services team is quite small.
- 💬 It shouldn't close, why change something when it works well? I see Haringey washing their hands of our users as they are soft targets. Where is advocacy support for individuals who don't have support from their families in these consultations?
- 💬 Carers shouldn't see this as a threat as it's transparent for advocacy support to be open and independent.



## Carers Focus Groups – The Haynes and Grange Day Centres

A joint Dementia Carers Focus Group was held for the Haynes and Grange Day Centres. **14** Carers in total attended. The responses below are what ALL carers said about the proposed closures and changes to the day centres.

<b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.	<b>Question 3:</b> Do you support Haringey Council's proposal to close the Grange Day Centre?	<b>Question 3 (sub question):</b> Please tell us why you feel this way?
	<b>Question 4:</b> Do you support Haringey Council's proposal to transfer the dementia day opportunities at the Haynes Day Centre to an external provider?	<b>Question 4 (sub question):</b> Please tell us why you feel this way?

### Carer – The Haynes



"I strongly disagree to any of the changes as I believe that this is a life line to these people. For the carers it's the only opportunity for a break and for the clients it's an opportunity to get out of the house. 70 million that they have to cut from the budgets. This is solely in the Council's interest. I'm extremely suspicious about all of this. Definitely shows a level that they do not have our best interests at heart."

### Do you support Haringey Council's proposal to close the Grange Day Centre?

14 Carers **Strongly do not support** the proposal to close the Grange Day Centre

### Do you support Haringey Council's proposal to transfer the dementia day opportunities at the Haynes Day Centre to an external provider?

14 Carers **Strongly do not support** proposal to transfer the dementia day opportunities at the Haynes Day Centre to an external provider.

**1 person remained in attendance to listen but abstained from voting or openly contributing to the meeting due to their lack of confidence in the facilitation; as they felt that the consultation should have been led by a dementia specific service.**



- ☞ Mother is 91 years old. She couldn't express herself before she came to the Haynes. She is now able to express how she enjoyed the centre. My sister took it upon herself to be her spoke person. Because of my sister my mum no longer comes here. She's now at home not speaking again. She's deteriorating. It feels like she's slipping away. The council need to intervene but they don't care.
- ☞ My Mum is in the late stages of Alzheimer's. She is double incontinent. If my Mum was to cease coming here and was at home she would deteriorate rapidly. She still has a quality of life. Even if she can't always show it, it still makes a world of difference to her and us.
- ☞ I can go to work happy because she's safe and I know that she is going to be alright. If she's at home with carer it wouldn't be the same as coming to the centre. They have far more interaction at the centre. This place is designed for people with dementia. It has an open plan. There are no stairs. Lovely garden. All on one level.
- ☞ Staff does a smashing job. I can't sing their praises any higher. They are very warm and dedicated to their jobs. They really care about the people at the centre. I can't imagine an external provider. I don't believe that it would work and that we would lose something. It would be detrimental to the clients and carers.

### Carer – The Haynes



"My mum used to come twice a week until her health deteriorated rapidly recently. During the process of recovery she needed to have extra carers to help at home; as a result of this Haringey Council have now reduced her day centre to 1 day a week to pay for her additional care. I've tried to get the Council to cut the hours of support. Their communication is very poor. They do not talk to effectively carers i.e. Even though I attended and after my mum was reassessed, the final outcome was not shared with me and I had to find out the necessary info via the paid carer."

- ☞ My mum does not have the ability to verbalise. She's not compos mentis. It's always a disadvantage for them. It's always hard to know what they want and to represent them as their advocate. Very difficult to pick up on the signals that they are trying to tell you as family members. So how much more difficult is it going to be for strangers to pick up on these facts? Coming to a place like the Haynes where you develop a relationship with people who were once strangers and the time it takes for them to learn how to communicate and interact. Once that's been broken the confidence for the client breaks too because they're constantly frustrated.
- ☞ People do not understand them. People often do not try and listen to them. People often do not know how to relate to someone with dementia. The person with dementia is trying to express themselves and often not being heard i.e. my mother will just shut down if she feels that no one is hearing her and she can't express what she feels. The way people speak is not understandable to people with dementia. It is organisations like this that are trained in dementia that make the difference. Any external organisation would have to be trained in the same way at all levels.

- 💬 These people were assessed to specifically be at the Grange. Why should you be moving anyone from there?
- 💬 Closing the Grange will put more pressure on the Haynes. The people that are here need to be here. They have been assessed to be here. Their dementia shows a continual decline. Why are you reassessing anyone?
- 💬 What are the eligibility criteria? Those that make the criteria will get in, what will happen to the others?
- 💬 The centres provide respite for carers and for the service user to get out of the house and meet people. This puts more pressure on the carers. Carers become isolated and depressed.
- 💬 They get on well with staff. They have their meals here.
- 💬 I think that somebody from the Council should come and do what we do and be a carer for a week. They don't know what we do because they don't do it. They are not there 24/7 with our loved ones.
- 💬 The timings of the meetings, were they made by the council? Time slots for the meetings at the Grange are later in the day and as the sole carer I can't go to a meeting as I need to be present when my loved one attends.
- 💬 I'm not related to the person I support. I do not think that the Grange closing is going to be of any help. The person I support has advanced dementia. He needs familiar faces. Why is the council trying to move them on? How is this going to help them? I don't think that this is going to give them a better quality of life in their last days.
- 💬 What are they looking for in regards to the criteria for people to be at the centre? Not after everything is said and done.
- 💬 I phoned the number to question the times of the meetings and they gave me the Manager's number. They said that "if you can't get through to him then come back to us, however the Grange may not close anyway?
- 💬 An impact is going to be inevitable on Haynes people. Feels like we have to compete. Not enough capacity and resources.
- 💬 The people at the Grange are possibly losing staff more than people at the Haynes because they are closing these services.
- 💬 For people at home – Home will become their prison as the carers have to work. I have to work. I depend on care carrying on. Only limited amount of time they can put in. Day centres allow carers to work. Possibly have to change my working hours.
- 💬 Carers who are ill themselves need the break. What about the ones that are already ill or disabled?
- 💬 They does not recognise the stress on Carers. Caring for a relative with dementia. People with dementia have very particular needs which are generally not the kind that can be supported in the community. Require specialist centres like this.

- Without any idea of what the alternatives are it is impossible to formulate/give a view. Until we have that kind of knowledge we can only assume.
- The issue for Carers – support in the community are the carers? Lots of pressure being put on the carers.
- At present the day centres provide carers with real respite ‘allows carers to have a life’. Will that be the case with alternative provision? What are the other criteria for the alternative provision?
- In whatmanner will it be run? Who will be running this place? Will the staff be getting a letter about voluntary redundancy?
- Why ask the question in the first place? No one wants it closed. Unless all come here.
- Personal budget, what will it cover?
- If this place was to shut down the donation made by the Haynes Trust will have to be repaid. £700,000 passed down to Haringey. Haynes Trust have the right to be involved in the selection of the social enterprise.
- The Haynes Trust is a small local grant making charity bequest by Lewis Haynes. Objectives set out the welfare of older people especially with dementia. April 1999 council and PCT came together for the support to build this centre. This place will stay open.
- This place is a state of the art place. We do not want it to be empty.

## Service User Workshops 1 and 2 – The Grange Day Centre (Service Users and Circles of Support – Carers and Staff)

<b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.	<b>Question 1:</b> Do you support the closure of the day centre?
	<b>Question 2:</b> What activities do you currently enjoy/do at the centre or in the local community with support?
	<b>Question 3:</b> Who helps to support you at the Grange?
	<b>Question 4:</b> If you had your own money (a personal budget) to buy services or activities would you choose to: 1) Continue buying a service like what the Grange offer? 2) Would you choose something different? (Alternative care) 3) Or would you mix it up? (a bit of the old and something new?)



## Carer – The Grange

“I wouldn’t be able to work; my mother comes 5 days a week without it I wouldn’t get any rest. My mum lives with me 24/. My mother can’t be left alone. The time at the day centre is the only break in the day. Unless the Council can provide the same service that is stimulating and safe then the carers will not support the closure. You talk to people, they’re not just dealing with the day centre here. The day centre is not their whole life. It’s not the sole problem of the person we care for... household problems everything. Life is not just fair.”







**Workshop 1 – 10 Service Users, 7 Carers**

**Workshop 2 – 11 Service Users, 8 Carers, 5 Staff and 1 Councillor**




### Do you support the closure of the day centre?

All 21 Service Users **Strongly do not support** the closure of the Grange.

### What activities do you currently enjoy/do at the centre or in the local community with support?

-  I socialise, it is a change of environment. Coming here has helped me to get away at least for the meantime, from home..
-  When mum's at home she doesn't do much. She's getting out of the house. She's meeting other people. It's cognitive stimulation.
-  I play games. Listen to records. Interact with the people. I go on trips out. Also discussing different countries and reminiscing.
-  They are busy doing things. Singing songs but they don't remember.
-  We sit with iPad looking at photographs from home. Talk about history and things that happened in the past. Jazz musicians came and we play percussion. Discuss different topics, moral issues, current affairs. Look at Countries of origin via the iPad – look at their history. I do various things, listen to records. Trips out, board games, sensory stuff, gardening.
-  My dad plays his guitar when other musicians come along.

### Who helps to support you at the Grange?

-  The keyworker.
-  He doesn't like drinking fluids. The only time he drinks is when he is here.
-  The staff here are very good.

- 💬 Most people come on the minibus. The Escort and Driver are very helpful and very friendly.
- 💬 One day transport broke down and I had to bring my uncle here. The journey was horrendous. Lots of traffic, pressure on me to bring him here on time as I had to go to work.
- 💬 I walk my mum here.
- 💬 Most people agreed that they use 'The Grange minibus' The driver and escort are very helpful, gets coats, bag and call 3 minutes before they arrive to the home to let you know to be ready.
- 💬 My wife supports me. She is my hands, my feet, my everything. My daughter is a big help too.
- 💬 I came from my house to this place on my own. That does not mean I do not use the bus but I came on my own.

### What would be the impact if they closed the Grange?

- 💬 It would be a terrible blow. My husband comes one day a week. It's the only time I get a break.
- 💬 I wouldn't be able to work.
- 💬 I don't want this place to be closed at all because it is useful for everybody.
- 💬 We as carers have our own problems too. We are older and have health problems of our own.
- 💬 My mum's at a stage where she doesn't know anybody anymore. She doesn't know her children. It's like she's in a deep sleep. She's agitated all the time.
- 💬 Being here is stimulating for them. It is helpful to socialise and just be out there with other people.
- 💬 I see the first choice would be the Grange because it all comes under one umbrella. It meets all of my mum's needs.
- 💬 What I don't understand is everyone has been assessed why do it again? There is nothing out there for people with dementia. Will it still be social care doing the assessments?
- 💬 There is nowhere else for me to go. You will jump out of the fire into the frying pan.

### Carer – The Grange



"I wouldn't be able to work; my mother comes 5 days a week without it I wouldn't get any rest. My mum lives with me 24/. My mother can't be left alone. The time at the day centre is the only break in the day. Unless the Council can provide the same service that is stimulating and safe then the carers will not support the closure. You talk to people, they're not just dealing with the day centre here. The day centre is not their whole life. It's not the sole problem of the person we care for... household problems everything. Life is not just fair."

- 💬 They are safe. Safeguarding is in place. She's not heading for the door. Having very caring staff here is more than we are able to do as we are not experts in dementia care. Here it is more convenient than in other parts of the borough. Here it is a dementia centre, they understand the clients.
- 💬 For my dad it would be the loss of excitement. I wake him up and he's excited because he's got somewhere to go. For him it's a part of his routine.
- 💬 His Alzheimer's has got better since he's been coming here. His memory has improved. He enjoys himself and for me, him having the structure has kept his Alzheimer's at bay. it will be to his detriment if it closes.
- 💬 Concerned, my mum comes here. She is one of the oldest people who does come. When she is at home she walks around like a lost sheep. She knows the Grange. We are worried what will happen next.
- 💬 When he is here he meets everybody. If I want to rest I can – I hope they don't close it down.
- 💬 I like the day centre. it makes me happy. I don't want this place to close down. All the staff are so nice, please don't close this place.
- 💬 For my husband it's the social aspect. The routines and the activities. He's eager to come. He understands the benefits of being here. Since being here is his routine he's more able to function. I will be devastated if it closes.
- 💬 He won't read the paper at home but he will read it here.
- 💬 As everyone said – the staff are brilliant.
- 💬 Where are we going to go? The choices could be 2-3 miles away. It's inconvenient. If the Council is closing all these services – where will they spend the money? The Local Authority need to keep this service. We can't afford private services.
- 💬 I can only relate to my mum. She doesn't recognise any of us (there are 8 of us). if we are in the garden she will try to leave as she wants to 'go home'. The problem is if we do not have a carer at home she walks up and down. She doesn't know where home is. Being at the Grange is helpful, just to be out.
- 💬 At home you have to find things for the person to do. My mum is on antidepressants, but all they do is lower her temper. The Grange safeguarding in a nutshell. Staff here shows affection.
- 💬 As a dementia centre, having a centre in the middle of Tottenham is vital. This place is unique, it is a dementia centre and they know what they are doing we are still learning. If transport isn't working, its local, we will get them here one way or another.
- 💬 When my uncle was in hospital he asked 'when am I going to be discharged to the Grange, not home the Grange. I do not think my uncle would accept a different service; change is so difficult for older people.

- 💬 The social aspect, networking, activities are important to him. He is eager to come. He knows the benefits of being here and he functions better when his routine is better.
- 💬 With my mum if I say 'read the paper' she says I read it even if she hasn't but when at the Grange I know she reads the paper and engages.
- 💬 The impression I get is that all the people here need an eye kept on them to be safe.
- 💬 Let me ask you – with more and more people getting dementia and Haringey currently has two specialist day centres, what will happen in the future.
- 💬 At the weekends I walk out of the room, but I get no rest because my mum follows me.

**If you had your own money (a personal budget) to buy services or activities would you choose to:**

- 1) Continue buying a service like what the Grange offer?
  - 2) Would you choose something different? (Alternative care)
  - 3) Or would you mix it up? (a bit of the old and something new?)
- 💬 You would have to look for somewhere with dementia (and there are only 2 centres in Haringey??)
  - 💬 LA keep privatising everything and everything is more expensive. I cannot afford private services.
  - 💬 The Grange is like a family situation, people are so accustomed to people here and it doesn't always work.
  - 💬 The whole consultation and proposal has been disappointing. The concept is not being considered. More people are living with dementia and I hope that in years to come, when they have nowhere for people to go they will realise what a mistake they have made.
  - 💬 I am not happy with the proposal
  - 💬 These proposals are really disappointing.
  - 💬 I have the impression a lot of people feel that the consultation is a cosmetic exercise and the decisions have already been made.
  - 💬 If the Council has lied to us and told us that they will listen to us and then they don't and close the Grange anyway it will show that they are liars who can never ever be trusted again.
  - 💬 It's not the money we need it's the resources.
  - 💬 Why don't they want to spend their money to keep the Grange open? Don't give the money to me use it to keep the Grange open.



Having been to the meeting they talk about alternative provision. We don't know about any other options. Is there any point being here (at this meeting)? I heard about the closure some time ago looks like it's a done deal to me. But the Council will regret it. It will be life threatening.

## Service User Workshops 1 and 2 – The Haynes Day Centre (Circles of Support – Carers and Staff)

<b>Proposal 3:</b> Increase the flexibility and availability of day services within the borough.	<b>Question 1:</b> Do you support Haringey Council's proposal to transfer the dementia day opportunities at the Haynes Day Centre to an external provider?
	<b>Question 2:</b> What activities do the service users currently enjoy/do at the centre or in the local community with support?
	<b>Question 3:</b> Who helps to support service users at the Haynes?
	<b>Question 4:</b> If the service users had their own money to spend on care services (a personal budget) would they choose to: 1) Continue buying a service like what the Haynes offer? 2) Would they choose something different? (Alternative care) 3) Or would they mix it up? (a bit of the old and something new?)

### Carers – The Haynes



"We have trust in the staff who responds to her needs. Continuity is important at this stage she is at. (No matter what stage they are at). Also safeguarding is an issue – how will Haringey police that? Who will look at standards? Who will monitor it from Haringey?"

"Sometimes there are problems. Service users can be absent minded. My person can pick up things that don't belong to him. Staff knows him and won't judge hi, for it. They can see the funny side of it. Will new be people be able to do that?"

### Workshop 1 – 6 Carers and 2 Service Users

### Workshop 2 – 3 Carers and 2 Staff

### Do you support Haringey Council's proposal to transfer the dementia day opportunities at the Haynes Day Centre to an external provider?

All 9 Carers **Strongly do not support** the proposal to transfer the dementia day opportunities at the Haynes to an external provider.



- 💬 My husband was diagnosed 4-5 years ago. He has his own care workers. A lady came to the door to say that she had been asked to come and put him to bed with a scrap of paper to do something for this man.
- 💬 How do they know the minimum impact it will have? They would need to do a feasibility assessment to know, otherwise how do they know?
- 💬 If the outcomes of the consultation will be in Nove/Dec 2015 who will be carrying out the assessments? Will it be a social work team?
- 💬 Let's cut to the chase, they will go for the cheapest option as they are looking to make cuts. I know this and this is the bottom line. They will make cuts on elderly services and disability but will invest in education.
- 💬 I don't think it's fair. The people have been looked after so well. I don't think we'll get anyone as good as we have at the moment?
- 💬 Are they going to change everything? They need to keep this place going and don't change anything.
- 💬 I am so used to the people who work here. You can talk to them, you can ask them things. They're like my family. Nothing is too much trouble. They are supportive. I am sure that no one else would care as much?
- 💬 If you start moving staff you don't know how it is going to affect people. Will people be on a decent living wage – when you have people paid next to nothing their moral goes up the spout. You'll have different carers every week.

### **What activities do the service users currently enjoy/do at the centre or in the local community with support?**

- 💬 (Service User 1) Cooking. I like cooking cakes. We share the cakes and eat them here. It's very exciting here. Dancing, singing songs, playing dominoes. It's very important how people greet you here. You aren't a number you are family.

#### **Carers – The Haynes**



“One of the beneficial effects of my mum coming to the Haynes happened 18 months ago. Mum stopped eating and drinking. With support from staff using visual cues and eating in a group my mum started eating again. That was very significant for my mum. It was a great concern to the community nurse but now she's eating again.”

- 💬 (Service User 2) we go out to the Garden Centre. It's lovely. We go to different places.
- 💬 Mum comes home and shares the news with me because she reads the paper.
- 💬 My husband has been here since 2010. His ability to participate has been damaged. Staff still try to stimulate him, encourage him and support him to participate. My husband was a good photographer. Staff took him out. He loved dancing, now the degeneration is changing him. So instead he is encouraged to remain part of the group – quizzes and dancing. He still is very keen to come here.
- 💬 When he first began here for the first 6-8months he had gone from 15 ½ to 17 according to the tests (at St Anne's). the final time we went back we were told that he did not have to come back again. That was the improvement he had made coming to the Haynes.
- 💬 The memory room is very good and useful. So is the sensory room.

### **Who helps to support service users at the Haynes?**

- 💬 Excellent! The place is clean and spacious. Mum uses her Zimmer frame and will not remember anything. Her coming here and meeting people of her own age also gives me a break.
- 💬 The people that provide the service have understanding, consistency and knowledge of the clients. The staff are excellent. Under the new proposal there won't be that consistency and no experience of staff.
- 💬 The staff here is not miserable. They are friendly with me and greet me. They are always nice to me here. She is quite active here and by the time she gets home she is exhausted. She looks as though she has had a good time? At the centre she is stimulated.
- 💬 He comes to the centre 2 days a week with the centre transport. Staff here are consistent, he is happy here. He has his lunch and does activities.
- 💬 (Service User 2) All the staff helps. They are lovely and they welcome you with a cup of tea. Whoever opens the door, you always get a welcome.
- 💬 (Service User 1) Haringey come and pick me up staff make sure we have keys and don't leave until we are safely inside. it makes your day coming here. A laugh and a joke make your day go round.
- 💬 For me it starts with the driver. He takes the care to make sure that she's ok. The staff are just so personable and skillful. When I came the other week the driver was doing a quiz with the service users. It not like the driver just drives. He's involved.
- 💬 From staff there is immediate feedback on how your loved one has been all day. How they functioned etc.

### **What would be the impact on changes to services?**

- 💬 I think that there will be lots of inconsistency for my mother. Voice recognition and the emotional support is important for her. It will be difficult for me. It will put pressure on me. Would the new providers keep/maintain the current staff?

- 💬 I think that any new provider will do it cheaply as much as poorly. It will not work. They will get people who do not speak English to communicate with the clients with dementia and disability.
- 💬 Where is the proof that social enterprises is effective anywhere with people with dementia? You can't find anyone anywhere ... can you?
- 💬 Transport ... will there be any transport? Can it be made sure that transport is included?
- 💬 Until recently my mother came in on the minibus, her mobility is such that we now have to use public transport. I have called dial a ride but they won't come to local Authority Day Services.

### Carers – The Haynes



As a carer continuity is both key at the Haynes and at home. I cannot see him passed on to other people. E.g. I was hospitalized and my husband was placed into a 'luxury retirement home'. He came home with a broken tooth, sitting in wet pads and had blisters. I was discharged a week early. Friends went to take him for a walk. No clothes could be found. He went out in his pajamas. Most staff was agency. I nearly didn't see the same carer twice. It took weeks for my husband to recover. Familiarity is important staff carers. All of this makes me very uncertain about external providers.

- 💬 My mum comes via taxi card scheme. She only gets a certain allowance and the drivers charges are extortionate. After that it would come out of her own funds.
- 💬 Because of my mum's dementia she wants to go to the centre but does not always want to get there on the minibus. Drivers/escorts are skilled, patient enough and will wait and work with mum.
- 💬 We can only respond to what is in front of us. We have insufficient evidence about social enterprises. Are all social enterprises charitable?
- 💬 The Haynes Trust will be involved in the selection of any social enterprise. There are a wide range of them.
- 💬 Several social enterprises are set up by staff and when I met XXX at a steering group she stated that staff will be supported to set one up.
- 💬 How would a social enterprise make a profit by increasing costs and reducing overheads? This is a Centre of Excellence. It needs to remain that way.
- 💬 Haringey as a local authority have a duty of care. They can outsource the resource but not the responsibility for the duty of care. What is the relationship between Haringey and any social enterprise? We need to know what the relationship will look like.

**If the service users had their own money to spend on care services (a personal budget) would they choose to:**

- 1) Continue buying a service like what the Haynes offer?
- 2) Would they choose something different? (Alternative care)
- 3) Or would they mix it up? (a bit of the old and something new?)

- 💬 The 2 service users in attendance said that they would spend all of their money paying to come to the Haynes. "I've been other places. I want to come here."
- 💬 All of the carers in attendance said that they would support their loved ones to spend a personal budget on the Haynes.
- 💬 My mother would not be able to answer that question. She would say "Ask my daughter?" I am not happy to answer this question until I do have a full understanding of what the offer is.
- 💬 Is the Haynes currently subsidised? If we get a personal budget would it be available for the day or just a few hours? We need to know if personal budgets will be ringfenced?
- 💬 I don't know if the personal budgets would allow for my husband's current level of service. I know he would want to come if the budget did allow.
- 💬 I don't know much about personal budgets but I know my mum wants to come here. I would also like to know what else is out there but even if I did know I think my mum would still want to come here.
- 💬 My mum has come here for one month. She was stuck at home but she enjoys coming here. She is more responsive, chattier. Until I see what is on offer it will be the Haynes.

## **6 OTHER INFORMATION**

For all matters concerning the outcomes in this report and anything in relation to the Haringey Council Adults Social Services 90-day consultation please contact:

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