

HARINGEY COUNCIL ADULTS SOCIAL SERVICES CONSULTATION - BUILDING A STRONGER HARINGEY TOGETHER

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

**Learning Disability Experience [LDX] Independent Advocacy
Support and Facilitation Outcomes Report**



Haringey Council

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GLOSSARY

Advocacy	An independent service which 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.
Advocate	The member of staff who supports the user/s of service to have their needs and wishes met and carried out in such a way as if they had spoken for themselves.
Carers, Family Carers or Parent Carers	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.
Council or Local Authority	Haringey Council or other Borough Councils
Customer	Resident or User of Service
LDX	Learning Disability Experience [Independent Advocacy Service]
Proposal	A plan or suggestion, especially a formal or written one, put forward for consideration by others.
Service [Service Provider]	A person or organisation that provides any form of health, social and/or community care service.
Service User	Anyone who receives any form of health, social and/or community services. Also known in this report as the User of Service, the Customer or the Resident.
Staff	The employee, worker, contractor and volunteer who carries out the service provision.
Stakeholder	A stakeholder is anyone with an interest or concern in Haringey Council services and business. Stakeholders can be any individuals, groups or organisations that are affected by the activity of these services or the management of the Council's business affairs.

1 INTRODUCTION AND BACKGROUND

1.1 Learning Disability Experience [LDX]

Founded in 1964, Learning Disability Experience [LDX], formerly known as Waltham Forest Mencap, is the lead provider of community learning disability support in Waltham Forest and the surrounding areas.

LDX is a well-established organisation providing holistic outcome-based opportunities for children, young people and adults with learning disabilities and other disabilities.

Based across 3 buildings and in the community, LDX employs 14 permanent members of staff, 40 sessional staff and 10 volunteers.

LDX's services are based around the 3 key structures of Information, Advice & Independent/Group Advocacy, Social & Leisure and Campaigning & Influencing. Within these structures we provide significant support in many areas.

Our **Vision** is of a world in which people with learning disabilities experience their basic human right to be fully empowered and included in society. We strive to achieve this by making it our **Mission** to exist in order to maximise quality of life and improve life chances for people with learning disabilities and those who care for them. We do this by:

- Providing information, advice and advocacy support
- Creating social and leisure opportunities and;
- Developing an attitude of effective change through campaigning and influencing

Our strengths show a commitment to making a difference to the lives of people with learning disabilities and their carers by maintaining the following **Values**:

We are:

- Efficient: we show value for money
- Accessible: we include everyone
- Empowering: we maximise choice and control
- Trustworthy: we are reliable and responsible
- Innovative: we are creative and imaginative
- Experienced: we are knowledgeable experts in our field
- Objective: we provide fairness and equality

1.2 Haringey Council Adult Social Services [HCASS] – Building a Stronger Haringey Together: Three Year Plan and Budget Consultation for Residents and Businesses [draft plan]

The Present:

Currently Haringey Council's Corporate Plan, **One Borough, One Future 2013 – 2015** sets the Council's priorities and outcomes, which are 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.

The Future:

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.

Proposals for the transformation of Haringey Council's service delivery model have been submitted and were open to consultation from 17th December 2014 to 18th January 2015. The Council did this to ensure that their users of services are aware of the proposed changes, how the proposals would affect them and to gather their views.

Haringey's Council Cabinet will meet on February 10th 2015 to recommend a budget to Full Council which meets on February 23rd 2015. Once the budget is agreed on February 23rd detailed plans and proposals will be drawn up over the next three years. Where they have an impact on service users or groups of service users, they will be subject to more detailed consultation before any final decisions are made.

2 PROJECT DETAILS

2.1 Summary Project Specification

LDX were commissioned by Haringey Council Adults Social Services 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 above consultation at the following corporate sessions **[Fig 1]** attended by Councillor Peter Morton (Cabinet Member for Health and Wellbeing) and Beverley Tarka (Interim Director of Adult Social Services) and specialist sessions **[Fig 2]** attended by users of services, carers and supporting staff.

The independent advocates will be expected to help 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 consultation sessions] is provided by LDX to Haringey Council Adult Social Services in the form of this report.

Fig 1: Corporate Consultation

Dates	Event 1	Event 2	Event 3	Hours
Monday 6 th January 2015	2:00pm-4:00pm Ermine Road DC 2 Ermine Road N15 6DB	5:00pm-6:30pm Ermine Road DC 2 Ermine Road N15 6DB		3.5 hours
Advocates/Facilitators	Ann S Weekes Louise Adams	Ann S Weekes		
Friday 9 th January 2015	8:30am-12:00pm The Roundway 20b Walthef Garden N17 7DX	12:00pm-4:00pm The Haven DC 20a Walthef Garden N17 7DX	5:00pm-7:00pm Osborne Grove Nursing Home 16-18 Upper Tollington Park N4 3EL	9.5 hours
Advocates/Facilitators	Ann S Weekes Louise Adams	Ann S Weekes Louise Adams	Ann S Weekes	
Total hours				13 hours

Fig 2: Specific Consultation [specialist sessions for users and carers of services]

Dates	Event 1	Event 2	Hours
Monday 12 th January 2015	9:00am-2:00pm Ermine Road DC 2 Ermine Road N15 6DB	3:00pm-6:30pm Lindon House 10 Linden Road N15 3QB	8.5 hours
Advocates/Facilitators	Ann S Weekes Louise Adams	Ann S Weekes	
Wednesday 14 th January 2015	10:00am-2:00pm Birkbeck Centre 2 Birkbeck Road Hornsey N8 7PF	3:30pm-7:00pm Osborne Grove Nursing Home 16-18 Upper Tollington Park N4 3EL	7.5 hours
Advocates/Facilitators	Ann S Weekes Louise Adams	Ann S Weekes Louise Adams	
Total hours			16 hours

Total Advocacy Hours Provided	29 hours
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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 who may come from all wards within the borough.

Approachable recipients did not need to meet the 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 or people with Aspergers.

Individuals and groups were assisted to:

- Understand the proposed changes to Haringey's Adult Social Services and involved spending considerable time with people, considering 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

3 EQUALITY MONITORING

LDX met with 85 people with a range of abilities either individually or as part of a group. A summary of participant profiles is set out in the tables below.

Identification

User of Services	52
Carer [in their own right]	33
Total	85

Gender

Male	21
Female	64
Total	85

Age Group

18-25	1
26-30	1
31-35	5
36-40	4
41-45	3
46-50	11
51-55	6
56-60	1
61-65	2
66-70	7
71-75	4
76-80	3
81-85	3
86-90	2
90+	3
Unspecified	27

Ethnicity

White British	12
White Irish	5
Caribbean	9
Black British Caribbean	4
Mixed White British/Black Caribbean	1
African	1
Asian	1
East African/Asian	1
Arab	1
Italian	1
Greek Cypriot	2
Turkish	1
Turkish Cypriot	1
Turkish/Kurdish	3
Indian	1
Philippines	1
Unspecified	40

Religion

Christian	3
Roman Catholic	9
Church of England	4
Seventh Day Adventist	3
Methodist	1
Muslim and Non Practicing Muslim	5
Greek Orthodox	2
Presbyterian	1
Non-Conformist	2
Alevism	1
Unspecified	54

Post Code

N4	4
N8	4
N10	4
N15	11
N17	16
N22	4
E3	1
E5	1
Lives outside of the borough	1
Unspecified	39

In addition to the above, 78 people were identified as 'Circles of Support' for users of services as they helped individuals and groups of people with learning disabilities, older people and other vulnerable groups to speak up for themselves and/or they spoke up on their behalf during the consultation sessions.

Circles of Support

Family/Carer	25
The Roundway Staff	13
The Haven Day Centre Staff	3
Ermine Road Day Opps Staff	14
Birkbeck Road Staff	9
Linden House Staff	7
Osborne Grove Nursing Home Staff	5
Residential Home Support Worker	2
Total	78

4 REVIEW OF INDEPENDENT ADVOCACY AND FACILITATION OUTCOMES

4.1 Council Proposals

People who attended the consultation sessions were very focused on expressing their views about specific services that were identified in the Haringey Council draft plan as proposed for closure or significant change. People wanted to talk about New Pathways for:

- Older People [Osborne Grove Nursing Home]
- Learning Disabilities [Linden House and Shared Lives]
- Day Opportunities Learning Disabilities [Reduction of building based day care]
- Increased reablement Physical Disabilities [The Haven Centre]
- Increased enablement Mental Health [Osborne Grove Nursing Home]

No person who LDX consulted with appeared to have prior understanding or knowledge of the broader picture of planned proposals for Haringey Adult Social Services up until their attendance at these sessions.

The proposals for the following did not come up as areas of immediate concern when addressed by LDX at the corporate or specific consultation:

- New Model for Care Management
- Care Purchasing Efficiencies
- Care Package Reductions
- Voluntary Sector Budget
- Healthy Life Expectancy
- Substance Misuse – Public Health/other
- Sexual Health
- Improve Public Health Efficiency

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 corporate and specific consultation exercises.

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 Questions

LDX asked individuals and groups that came to the consultation sessions [in various accessible formats] 3 questions:

- If Haringey Council goes ahead with all their plans ... How would it affect your day to day life?
- How do you feel about the plans for Haringey Adult Services? [Based on the responses given in the first question]
- Why do you feel like this?

5 FEEDBACK FROM HARINGEY COUNCIL ADULTS SOCIAL SERVICES 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 THE HAVEN CENTRE DAY CENTRE



Service User – The Haven Day Centre

“I am diagnosed with dementia. I didn’t want to accept it at first. It was rough. Professionals came and went and they did what they did. You followed what was being done to you.

I came to England from Africa. I was training to be a nurse but had to stop because my father arranged my marriage.

I go to the Haven 2 days a week Thursdays and Fridays. I learned how to read, sew, crochet, knit, embroidery; all at The Haven. Drivers take me Door to Door. I get a 2-course meal. I don’t need to eat again when I get home.

In the past I hurt the people who were looking after me because I didn’t understand what they were doing. I didn’t realise people were monitoring me to help me. I learnt how to respect others more than myself. I learnt this at the centre.

My daughter is my carer but she has a husband who is very ill and doesn’t have the time to look after me full-time. Elderly people have families who cannot support them because their families have their own problems too.

It’s very nice to come here. If we don’t come we’ll go back to square one. If the centre closes I’ll be on my own most of the time and I’m scared because I have mental health problems.”

Users of Services General Comments – The Haven Day Centre

User of Service – The Haven Day Centre



“This day centre means the world to me. My mother came here and that’s why I came here. Where is it going to put me? Out on the street?”

- 💬 What exactly are the proposals as they are not very clear?
- 💬 Will new services be more expensive to run?
- 💬 Will it be possible for Haringey Council to look at other Councils to see how they use their budget?
- 💬 What about the people who can’t get out and walk? This is what places like The Haven is for.
- 💬 We come here to socialise.
- 💬 Everybody in this room has worked all their lives. Now that we are non-productive you want to throw us to one side.
- 💬 Everyone keeps telling us that we worked too long.
- 💬 I don’t think it’s worth listening to you Councillor.
- 💬 I’ll stand out in the street.
- 💬 The day centre is family.
- 💬 Why don’t you do away with one Councillor per ward and use the money to save services? You’ve already made lots of staff cuts so maybe it’s time to cut Councillors.
- 💬 This is very devastating news. I was very active until my accident on the building site. I had to give up my allotment and most of my activities. I don’t like to be indoors. I would lose my social life.
- 💬 The Haven is a nice place. I wouldn’t like to lose it. Not one bit.
- 💬 All my friends are here. I love it here.
- 💬 I wouldn’t like to leave here. They are good to me. They pick me up and take me home. I wouldn’t be able to get around if they didn’t do that kindness for me.
- 💬 It has made such a difference to my life being here. My wife and I used to come here. She died last year. She was my beautiful flower. I would be at home on my own if I didn’t come here. I have my friends. I like getting together and socialising.

- 💬 I'm a very happy lady. Very grateful for my life. My main thing – why are we being cast aside? We are old people and they think that they can do what they like with us.
- 💬 You don't want people coming to your home? Majority of us can't come or get out on our own. Makes me feel like I am not human anymore.
- 💬 Not happy, I like coming here. I enjoy the company. I come twice a week. Rest of the week I am at home. Keeps me occupied. I buy second-hand things here.
- 💬 I look forward to coming here. I come four days a week. Such a nice crowd. If I did not come here I would be a little depressed. I gave up driving, I use a walking frame I won't go on the bus on my own. I would not be socializing.
- 💬 This is the only bit of enjoyment that I have.

Users of Services Individual Comments – The Haven Day Centre



User of Service – The Haven Centre

"I feel sad about the proposals. I feel sadness. I am sympathetic to the views of everyone, as I understand how they feel. I would feel cheated if they closed the Haven because I would have nothing to look forward to. I come here 2 days a week. Thursdays and Fridays. That's not a lot, is it? I don't think the reasons for closure are good enough. The financial reasons for making savings are not good enough.

The Council could rent the building out to make more money. Don't they have empty buildings and assets that can be rented out to generate money? Being on your own makes quite a difference to the way you think."

💬 Service User 1

I was really ill. I went to a private doctor at The Priory for a long time. I then went to a day centre at St Anne's Hospital. It was horrible. I then went to Woodside Day Centre for 6 years and then they closed it down. I became very depressed. When I was really ill I never left the house. I lost my skills. My son did everything for me.

I have now been at The Haven for 4 years. I come here 5 days a week. I have settled in. The Haven opening was like winning the lottery. I am very aware of things now. I have lots of confidence.

When I come to the day centre I play dominoes and tri-ominoes. I mix with other people. I go on trips. I love going to Ikea.

If The Haven closes I'll go back to square one. I'll end up like a cabbage again. The panic attacks and depression will come back. Some of the homecare workers are useless. The Haven is the best care in the world and I look forward to it. It will be really sad. We're like a family here. They are my family.

It will be the death of some of us.

Service User 3

I lived on the settee for 5-6 years. My son had to leave work to look after me. I came to this centre. This is my second home. Who will look after me? If you do close it down I will be back where I was. I was at Woodside. It took me time to get used to this place. I won't be able to leave the house again. My son has bills to pay. No one will look after me.

Service User 4

If I feel sick they make me feel better. I won't eat – I have diabetes, they make sure I eat regularly. It will kill me. It will make me ill again. I get very panicky. Wonderful staff, wonderful management. The Haven gives our children peace of mind knowing that we are coming here.

User of Service – The Haven Centre Day Centre



"I appreciate everything the council has done for us. Please don't close the centre – I have learnt so much here, please do not close this. Many of us need this without this we cannot survive. When I get home I am very lonely. The manager encourages us. Please Sir, I am asking you to help us – without this we have nowhere."

Service User 6

If people don't want to listen they will listen to me. Staff has been good to me. Everybody here has been good to me. I think the world of this day centre. I'm telling you this much the other week I left this centre it was really cold, I ended up in hospital. People from this centre did not know where I was. I was nearly on my deathbed if it was not for these people and these drivers. This day centre means the world to me – more than anything. I know a lot of people here and they are all kind to me. What will happen to me? Please, please I want this day centre to stay open.

Service User 7

If you are going to keep a place open then keep this one open. Everyone here loves coming. It is a big family. It will be sorely missed if you get rid of it. My family have been in Tottenham for over 100 years and this is what you are doing to us. We pay our taxes. When I came here it absolutely changed my life. I had two days. I could socialise.

It's not the same at home and talking to someone on the phone is not the same as seeing someone. We might be old – but we are still human. This is a lifeline.

 Service User 8

My daughter and granddaughter are my carers. When I am here they can relax knowing I am OK. We are constantly hearing about the aging population. I thought I would be settled here for the rest of my life. I love coming here. When I am at home I am very lonely.

 Service User 9

I come here once a week so it won't affect me much. I listen to the radio at home on my own. At home I have meals on wheels they are not very nice. The food here is good. I enjoy the food. I meet other people. I have a home help at home twice a day. She talks to me. If I didn't see her I would not talk to anyone. I would miss this place if it closed. Makes me feel sad because it is such a good service.

 Service User 10

Be a shame if they close this place. I come here 3 days a week because I am lonely at home. Bus picks me up I don't go out on my own anymore. Walking is a struggle. I enjoy the company. I worried about this because I will have no one to talk to during the day. I would be very sorry if they close this place. They encourage us to go to the Doctors. They keep an eye on us if we are not well.

Carers – The Haven Day Centre

Carer – The Haven Day Centre



"Can we not share this building? You have an extension there. Why can we not share the building? How many people out of hospital do you think you will be getting? I understand people need rehabilitation. Give us an alternative. Let's leave these people a little bit happy. Let's share this building. At least these people will have somewhere to go and to keep warm and to have a proper meal."

 This centre is amazing. My mother comes here. Have you thought about the people who come here?

 Cuts have previously been made and adult social services frontline services should be protected.

 I'm representing my parents. If my dad didn't come here it would kill him. It would also kill us. You're using people, children with disabilities or adults with learning disabilities. People sold houses and pensions to pay for their care. What are you going to do with all these people? Who's going to pay for staffing to care for these people? They will be stuck in their homes?

- ☞ I've come out today because it's so important. Mum suffers from Alzheimer's and before coming here for a long time. I am her sole carer. She hardly spoke a word before then. Mum attends 3 days a week and she's made friends. My mum joins in as much as she can, she will regress again. I've been able to go to work and I pay my taxes. My mum loves this place. For lots of people their main meal is here. I'm still a carer for my mum, some people have nobody. What I am grateful to Haringey Council for is bringing my mum back to me. Give them an alternative. If you want more money I will pay more money. Keep these services open. We don't want you to close this place. Not 6 months or 3 years down the line.
- ☞ My mum comes here. I would have loved her to come here twice a week. She comes once a week. This is the legacy of overspending over many years; how people in government have dealt with the finances of the people.

5.2 LINDEN HOUSE

Linden House residents are unable to speak up for themselves. One resident did not want to talk and the others were unable to. Another resident is also affected by possible changes within another service and had spoken with us during the day.

Staff and family carers were identified as 'Circles of Support'. They spoke up on behalf of the residents.

Session 1 – Circle of Support Linden House

If Haringey Council goes ahead with all their plans ... How would it affect the resident's day to day life?

Circle of Support – Linden House



"No one has shown anxiety or distress as yet because they don't understand what is about to happen to them and their home. How can they understand? The explosion will happen if and when they move. It will be a tremendous explosion. It will happen in a matter of days. Only then will the impact really be felt."

- ☞ We explained to the residents that there may be some changes happening but it meant absolutely nothing to them. This group has no understanding of what's going on. There has been little immediate reaction because they had no idea about what we were telling them.
- ☞ The residents have been here a long time and they are settled. Some residents have been here for over 7 years. They can't speak up for themselves.
- ☞ The move from agency to permanent staff was an excellent move. The home has come on leaps and bounds. The permanent staff team have been here for 4 years. We've worked hard with the residents to help them settle and learn about their needs and choices.

We have significantly reduced their challenging behaviours. All staff took beatings, bites, spitting, smearing and cursing from the residents to get them to where they are now and we'd do it all again because we know what has been achieved for the residents so that they can have an excellent quality of life. They get social interaction from us that they won't get anywhere else because no one else will want to work with them in the way that we do.

- 💡 Because of their autism and challenging behaviour, some residents will only accept support and personal care from specific staff. They go to staff who they recognise. It's taken a very long time for them to build trust with us. It's taken years for some residents to get to where they are now.
- 💡 The changes will have a profound detrimental effect on the resident's health and well-being. It's going to be very hard for all of them. Some residents have been passed around and they have now settled. There will be extreme challenging behaviours. They will digress. They will be put through unnecessary hell.
- 💡 Noise levels and certain behaviours of the residents are unmanageable in the community. Some individuals can be a danger to themselves and to others if they are not carefully supported. They are not suitable candidates for Shared Lives/Supported Living. These residents need 24 hour care support and bespoke services. Safeguarding is a real concern.
- 💡 If Shared Lives doesn't work residents will get forgotten. They may get chucked in an older people's home, a mental health unit or sent home to unmanageable situations.
- 💡 Some residents have physical needs. Some are not able to get around like others.
- 💡 This will have a negative impact on family orientations. All families will suffer. The clients will feed off their anxieties. Families depend on good staff to care for their loved ones.
- 💡 Some clients have known each other since childhood. They went to school together and have gone through the 'system' together.
- 💡 If the home closes it won't be good for everyone involved.

How do you feel about the plans for Haringey Adult Social Services?

Circle of Support – Linden House



"Residents will be devastated when they realise what's going on. They may feel abandoned when they don't see any of the staff and they realise [in their own way] that we're not coming back or not there anymore. Residents will withdraw and their mental health will deteriorate.

- ☞ The council is taking away the resident's experience in exchange for profit or savings. It will have a detrimental effect on their health and well-being.
- ☞ It is difficult to say much else without more information. There are not enough details and a lot of speculation. The information coming through is vague and inconsistent. Staff feel unsettled for the residents and closer to the time we will have to draw on all our skills to try and help people to understand. For the resident's sake we really hope the Council doesn't go ahead with the closure.

Why do think the residents will feel this way about the plans?

Circle of Support – Linden House



"It will take a very long time for residents to resettlement; if they do at all?"

- ☞ It will be a huge learning process for any new staff team working with residents. They will need to be very experienced.
- ☞ The neighbours have become accustomed to the residents. The manager has worked hard with the neighbours to manage peace controls, as they sometimes get upset about the noise levels. Residents can be extremely loud. They need to be in an environment where they can be free to express themselves. They need space when their behaviour becomes challenging and when they are no longer able to manage their own behaviour. The new neighbours won't know what has hit them.
- ☞ The residents are not going to experience real choice and control because they are being 'sent' to a new place. They don't get to choose where they go. They don't get to choose their new home.
- ☞ Residents will digress. It will be too hard for many. They need consistency.

Session 2 – Carers Linden House

If Haringey Council go ahead with their plans ... How would it affect your loved ones' day to day life?

- ☞ Try to be realistic [staff have told me]. They look out for me as a carer. When Linden House closes will the same staff go to Muswell Hill? Will staff lose their jobs? The staff has a risky job. For the work they do they should be paid more money not losing their jobs? They are not being paid their worth.
- ☞ There were lots of problems in the beginning at Linden House. The agency staff caused so many problems. We were always worried. It took years for the clients to settle. The new staff that came in is much better. The clients are now happy. I have seen a big change in my son.



Carer – Linden House

“The previous manager and staff were not very good. Now it’s wonderful with the new staff and manager. It’s much better now there is full-time staff. The staff at Linden House is perfect. They do everything. I’m too old now and can’t look after my nephew.

You will take my nephew somewhere he doesn’t know. He will become very aggressive like before. He’s used to his current surroundings. Why destroy him? I understand that savings have to be made but leave Linden House alone.

My nephew knows staff and staff know him. He will be confused and will start hitting people again. I am concerned that staff who do not know him and who are not trained will start hitting back [when no one is looking].”

-  The people who live here need 24-hour supervision. They can’t understand and will become very aggressive. People have bespoke complex service needs.
-  There should be a way to make the cuts that does not include our loved ones. The Council is making cuts but it’s our loved ones and us who will be bleeding. We pay our taxes so why can’t they find another way to make savings? Haringey doesn’t have money but they have lots of managers.
-  I went to see the proposed building at Muswell Hill. It looks totally unsuitable. It will not be familiar surroundings. How does the Haringey evaluate who is suitable for shared lives? Will the new home be monitored? What will happen if Muswell Hill is not suitable? Are there any other places?
-  I read somewhere that if the worst comes to the worst people will be sent home to live with their families. Parents will have to give up work. We would lose our jobs. We cannot depend on benefits. No one helped me when I needed the money now they want to take it away. I would not be able to look after my son at home. He is too strong for me. My health would deteriorate. My family would suffer.
-  Staff work very hard to achieve the quality of service. The old staff team was very inconsistent in the past, it has been a hell of a job for me.
-  Why the consultation is so short and why was it during the Christmas Holidays? I think the proposals should be challenged. We can’t allow this to happen.

How do you feel about the plans for Haringey Adult Social Services? [Based on the responses given in the first question]

Carer – Linden House

“Impossible! I won’t accept it. Leave Linden House alone.”



- ☞ We feel stressed and distressed.
- ☞ Frightened.
- ☞ We will have to give up our jobs.
- ☞ We don’t trust the Council.
- ☞ We feel that there is no room to challenge Haringey.

Why do you feel this way about the plans?

Carer – Linden House

“We are annoyed because the Council keeps doing this to us and to our loved ones.”



- ☞ The clients won’t be able to do the things that they do now. They find it hard to meet new people. They are strange faces. They will have real problems settling. Our sons would lose their friends they’ve been with all their lives.
- ☞ It would be criminal if something happened. People should not be moved until death. I would like my son to stay here as he is.
- ☞ I believe that Haringey Council has already made up their mind. They are in the habit of making promises but they couldn’t care less. The council are not thinking about the people who live at Linden House.

5.3 OSBORNE GROVE NURSING HOME

User of Service – Osborne Grove Nursing Home

“The dissemination of information is very poor. There is an assumption that because we are service users we are not intelligent and we don’t understand what’s going on. That may be the case for some of the people who live here but not for everyone. Not for people like me. I understand.”



Users of Services – Osborne Grove Nursing Home

If Haringey Council goes ahead with all their plans ... How would it affect your day to day life?

-  I'm concerned that if you're going to bring in a mixed population the service will be diluted. If it's gradually going to change its nature how are they going to manage this?
-  My wife has been here since 2008, since it opened. She has to be here. She was a bed blocker in hospital. Her needs cannot be met in the community. I used to care for my wife for a number of years. I can't now due to ill health. I come to see her almost every day. She requires nursing care, nursing home.
-  There are 4 units all high dependency and some with higher needs than others. The people who live here, will they continue to get the same high level of care as what is currently received? What about redundancies? Will all the staff be made redundant?
-  My sister helped me to look at untold amounts of nursing homes before we settled for Osborne Grove. Most of them were not suitable for my needs and others would not take me.
-  The staff here are very willing and caring. Osborne Grove is an example of best practice. It would be tragic if Haringey Council let Osborne Grove close.
-  I do not know where people like me with high support needs will go? The private sector does not want high support needs like me. I had lots of care in the community but I still had to come here in the end?
-  My wife and I live at Osborne Grove. We were at another home but my daughter did not like it there. The hospital felt that I needed to come here. My wife has dementia. She has to be on her own. I see her every day.

How do you feel about the plans for Haringey Adult Social Services? [Based on the responses given in the first question]

User of Service – Osborne Grove Nursing Home



"This place is good to me. This place is nice. The staff is nice. The food is nice. I do not remember who brought me here?"

-  I am very nervous for my future.
-  I have mixed feelings about being here. I don't care about me but I am very worried about what will happen to my wife. She's only alive because she's here. She will die if she has to leave.
-  I'm really worried about the timeframe for when all of this is going to happen. It's like having the sword of Damocles hanging over me.

- I would like a clear timeframe that lists all the different things that are happening and when. I'd like to know when decisions will be made and if changes are agreed, when those changes will come in to effect?

Why do you feel this way about the plans?

User of Service – Osborne Grove Nursing Home



"People are living longer. Carers in the community don't have enough time to support people like us. They have appointments back to back. They cut short their appointments with us so that they can make time to get to their next appointment."

- If they plan to use the same staff for reablement services, management at Osborne Grove will be split in their responsibilities. As the Osborne Grove residents gets smaller and patients leave or die what will happen to those left behind? Will we be left in a back room somewhere?
- According to the hospital I cannot stay at home or look after my wife because of my own health needs. As far as I'm concerned I just make up the numbers. My daughter speaks up for me but she couldn't make it. I have nowhere else to go. This is my home but it's not the same as your own home.

Carers – Osborne Grove Nursing Home

If Haringey Council goes ahead with all their plans ... How would it affect your loved ones' day to day life?

Carer – Osborne Grove Nursing Home



"I would like to stress what a hard and upsetting experience it has been. Haringey nursing care provision is not great but it is home to many. Day services are as 'cheap as chips'. You don't need to close them. There's going to be nothing left. I don't care what Party people support you all need to get together and sort this out."

- People at Osborne Grove have high dependency needs. If they're not going to stay here where are you going to house them? The residents' lifestyles are being threatened. It is unsettling for everyone. It's all a bit vague.
- The demographics won't change. People will still be ill. There are only 2 other residential nursing homes in the borough and both have failed their CQC. People will have to be shipped out of the borough.
- I'm very hands on with my mum and the staff. This helps everybody pick up what's required to support her. If you move people out of their environment it will bring on mental stress. No one is prepared for this and it's a medical fact that once you move sick people they die. Haringey Council would not be able to provide what is medically required for our loved ones out in the community.

They have higher needs and require specialist medical care. Most relatives have had to fight tooth and nail to get their families in to Osborne Grove. The home has all the potential to stay without loss of money. Everyone's supposed to be working as a team instead of at loggerheads. It is a good home it has all the pluses. Where's the contingency plan. How are you going to look after these people in the community?

- 💬 You haven't done re-evaluation of all residents involved. You're going to decide the budget first and then try to organise the services.
- 💬 This makes a mockery of consultation. This should have started months ago.
- 💬 People like my sister are going to need somewhere to be looked after.
- 💬 Care homes providers are obliged to accept what the council gives. Services suffer as a result. Some care homes are business orientated.

How do you feel about the plans for Haringey Adult Social Services? [Based on the responses given in the first question]

- 💬 Concerned and worried. If less people are here there will there be fewer nurses? It is very stressful looking after someone with dementia.
- 💬 I'm scared. Not only for my family but for everyone – they should not close Osborne Grove. It's a great facility.

Why do you feel this way about the plans?

Carer – Osborne Grove Nursing Home



"I have gone round homes here and in Yorkshire somewhere pretty grim. People do not understand the implication."

- 💬 Publicity about this consultation is lacking. Whole thing is rushed. We've been off for Christmas for 3 weeks. This has been pushed through by the Council. Very few people in this home have people who are able to speak up for them.
- 💬 This place was purpose built and opened by the health minister for people with dementia. What happens if you are not well after the 6 weeks?
- 💬 The staff always has to consider the safety of the people who live here. Everybody bar one person needs care in a place like this. How are they going to look after those people who remain? Will they have the correct facilities? No one knows when they will die but the Council is banking on people dying quickly. If the people here are not here they will be in hospital.

5.4 ERMINE ROAD DAY OPPORTUNITIES

Most of the Ermine Road Day Opportunities users of service were unable to speak up for themselves. LDX was able to identify 10 people to have a discussion with.

Staff and family carers were also identified as 'Circles of Support'. They spoke up on behalf of the users of services.

Session 1 – Users of Services, Ermine Road Day Opportunities

Based on the question: If Haringey Council goes ahead with all their plans ... How would it affect your day to day life? We asked people **“What does the Day Centre mean to you?”**

User of Services – Ermine Road Day Opportunities



“I like it here because it makes me happy. I enjoy myself. I like the people.”

[In the users of services own words and supported by staff]

- ☞ Got nowhere else to go
- ☞ Develop friends.
- ☞ Daily routine, I will lose it.
- ☞ Big change. Have routines.
- ☞ I will lose my self-confidence.
- ☞ Happy.
- ☞ Trust the people at Ermine Road.
- ☞ Come in for 2-3 days but better services.
- ☞ I like to come to the day centre to see my friends.
- ☞ It's my routine.
- ☞ Will affect my confidence and health.
- ☞ No one understands cant? ... what this will look like.
- ☞ Research about outings and activities.
- ☞ I like it here.
- ☞ I like to come here – I do different things – I enjoy going out.
- ☞ I go from home to here for 5 days.
- ☞ Not happy to have change.
- ☞ 1 or 2 good sessions but rest of the time babysitting
- ☞ I like coming here, I lost weight, I go swimming, I go cycling.
- ☞ (a drawing of a house)
- ☞ I would not be happy if I was at home all of the time. I get upset if I can't come.

User of Services – Ermine Road Day Opportunities



“If I don't come to Ermine Road I would have to stay at home.”

Based on the question: How do you feel about the plans for Haringey Adult Social Services? [Based on the responses given in the first question] we asked people “How would it make you feel if the day centre had to change your service?”

[In the users of services own words and supported by staff]

- ☞ Sad
- ☞ It makes me feel sick, sad and angry.
- ☞ I will fight [gestured fighting].
- ☞ [Gestured] tears – sad.
- ☞ [Gestured] I feel sick.
- ☞ Pointed to picture of Ermine Road. I feel upset and unhappy. [arms raised]
- ☞ Makes me feel bad.
- ☞ I would feel angry.
- ☞ I don't want to lose my friends.
- ☞ Lonely.
- ☞ Not fair up and down. Keep on making changes. Every time I get used to it they change things again.

Based on the question: Why do you feel this way about the plans? We asked people “Why do you feel this way?”

[In the users of services own words and supported by staff]

- ☞ I want to stay here – I love all the things I do here.
- ☞ I want to stay where I am – it's all I know.
- ☞ Being at home is like being in a cage.
- ☞ I'm used to being at home, nowhere else to go.
- ☞ It makes me feel unwanted and used. The staff mean a lot to me.
- ☞ I've been coming for 16 years – it's a part of my life.
- ☞ I was very unhappy took 5 years to settle.

Session 2 – Circle of Support, Ermine Road Day Opportunities

If Haringey Council goes ahead with all their plans ... How would it affect the users of services day to day life?

Circle of Support – Ermine Road Day Opportunities

“People need to take a holistic view when looking after the health and wellbeing of the service user. There are such high needs here. A lack of consistency affects deterioration of behaviour. It's not that simple for people with learning disabilities being out in the community.”



- ☞ The day centre will need skilled, motivated staff to continue to co-ordinate the sessions for service users and who will facilitate them? i.e. Hydro pool + rebound therapy, sensory support, cycling and art scope etc.
- ☞ How will service users have access to personal care in the community?

- ☞ We cannot reassure our client groups who have some understanding because we don't have enough information. Everything is too vague. It would be nice to have more concrete information to make available to parent carers.
- ☞ What appropriate community services will be available? The local community is still not as accessible as people think it is for people with learning disabilities. Clients may become de-skilled if they get less support to be independent.
- ☞ Safeguarding - We are the first port of call for service users and carers. We can identify concerns with clothing, bruises, not eating, health deteriorating, money not being paid etc.
- ☞ Carers are very concerned that the model works for them and their loved ones. For some of the parents this is all too much for them, they are asking what does it really mean?
- ☞ Parent carers need as much support as the service users do? Some of them are really elderly. They physically can no longer do things anymore. As a gesture of good will and beyond the call of duty we support them with many things during the day including taking clients to the foot clinic, the dentist, picking up prescriptions, keep a check on health and well-being issues and remind families of important dates and appointments etc. Parent carers have confidence in staff and there are longstanding relationships that would be hard to recoup.
- ☞ How will the community be regulated to make sure that people are safe? Safeguarding will be a huge issue. Who will be responsible for checking DBS in the voluntary sector?
- ☞ There will be a huge impact on behaviour with clients hitting themselves and others.

How do you feel about the plans for Haringey Adult Social Services? [Based on the responses given in the first question]

Circle of Support – Ermine Road Day Opportunities



"Regulation – how do you know people are doing what they say they do? Safeguarding needs to be put in place around the 'model of social enterprise'. In the voluntary sector who will be responsible for co-coordinating/ checking DBS?"

- ☞ Care in the community – It doesn't feel a lot of financial planning has gone into this?
- ☞ Feel that Haringey council is trying to pull the wool over the eyes of the parents/ carers.
- ☞ Service users' self-esteem and health will suffer.
- ☞ Bit by bit would have been better than cuts all at once.

☞ Parents/ carers are being dragged through the system again.

Why do you feel this way about the plans?

- ☞ Vulnerability – Concerns for the future, the unknown. People are hyper vulnerable.
- ☞ Sustainability – This will happen, this is just the start
- ☞ Health will deteriorate – unhealthy impact on health and wellbeing.
- ☞ Constructive vulnerability – Making people more vulnerable than what they are already.
- ☞ Collateral damage – people will deteriorate and possibly die if their care package is not there anymore.
- ☞ Fearful – unknown for the S/U uncertainty. What will happen to them?
- ☞ This is unfair, why? – because these kind of changes are unfair.
- ☞ Stress and strain on all staff will manifest itself in the service users in other ways. We will feel the pressure
- ☞ Abandonment – because it feels like everything the service worked for, has achieved and produced will be gone. Resources will disappear.
- ☞ We are here because we like to look after the needs of our service users. It's never been about the money. If our jobs go we'll get another one but what about the people with learning disabilities? We do it for them. We do it because we care.
- ☞ It's going to be hard to be positive until we see the action plan and outcomes.
- ☞ There is still a lot of negativity and barriers in the community. Many people and services still have a negative view of people with learning disabilities.

Carers – General Discussion

Carer – Ermine Road Day Opportunities

“My son has spent 6-7 years in the care home. He was active before this. My daughter asked the home “What activities does he do?” Besides the cinema he doesn't have any other activities. It is a nice clean home but no activities.”

- ☞ It is important that my son has access to social and day opportunities including going out with groups.
- ☞ They want to close down Ermine Road. My daughter went into residential care. She had no day services for 4 years. She needs more assessment.

The residential home do not help her during the day. They make excuses i.e. have not got staff or transport etc.

- 💬 Would it not make sense to have a 1 year instead of 3 year plan? The Council should wait for outcome of general election before making any decisions?
- 💬 I take offense to the consultation being done over the Christmas period. We don't have time to consider these things during this period.
- 💬 The documents we received don't explain what Beverley Tarka explained today at the consultation. The wording is confusing. It doesn't say "Day Service" it says "Day Centre". It's misleading (consultation document).
- 💬 Carers are not supported enough to support my son whilst in care home. This is neglectful. There is not enough day centres for people like my son. I don't have peace of mind about my son. I am very disappointed.
- 💬 My son is in Ermine Road. He knows how to do work. He can file etc. The social workers keeps saying they will help him in 1 year. I call and nothing changes. The Council have spent time and money for him to go to college etc. but 4 years later no change. He goes to Ermine Road and then he comes home. Every day is the same thing. He's not doing anything. He has forgotten how to do things. He is getting lazy. He could easily, with support, do 2 hours a day working. He can work.
- 💬 I had a lot of trouble getting my son social activities. If this proposal goes ahead it will be very difficult.
- 💬 My son loves to come to come out during the day. I am 69 years old. It will kill me if he can't come here anymore. He is in his room when he is not coming here. My son does not sleep at night so I get to recover when he comes to the day centre. I want more services not less.

5.5 THE ROUNDWAY SERVICE

LDX spoke to 6 users of services at the Roundway. The remaining users of service were unable to speak up for themselves.

Staff and family carers were identified as 'Circles of Support'. They spoke up on behalf of the users of services.

Session 1: Users of Service, The Roundway Service

User of Service – The Roundway Service

"Oh no why? ... If you cannot, please don't. It's not fair – I won't be happy. Don't want to miss the centre."



Based on the question: How do you feel about the plans for Haringey Adult Social Services? [Based on the responses given in the first question] we asked people “How would it make you feel if the day centre had to change your service?”

[In the users of services own words and supported by staff]

-  I feel sorry
-  I love my activities. I don't want to stop doing them. I loves cooking.
-  It can't be happening – why?
-  They help me go out.
-  I'm afraid it's going to happen
-  I would feel stressed

The users of service did not want to answer any further questions.

Session 2: Carers, The Roundway Service

If Haringey Council goes ahead with all their plans ... How would it affect your loved ones day to day lives?

Carer – The Roundway Service



“My daughter was taken out of services for a while. Staff had to call the police because they could not deal with her. If staff who knows her well can't cope how are strangers going to manage?”

-  When a stranger comes to pick my child up I would not allow it.
-  My daughter lives in at residential home. Will she lose her day service? Structure meaning routine to her day.
-  My one would think she could go into the shops and help herself to things. She doesn't understand that she has to pay? If she has to stay at home it will have a negative impact on her. It's another change to her routine.
-  We won't be able to go anywhere. It will restrict our movements. My son becomes destructive when he is affected by change.
-  All clients are different they are not all the same. They all get tarred with the same brush. My daughter does not understand. When things are very bad she ends up spending time in a Psychiatric residential home. The last time she spent 9 months there.
-  My daughter has been a part of these services for 11 years she is used to this. It should be replaced by something better not worse. What will she do if she can't come here?
-  If they close the day centre I will have to take my son out of services.

- 💬 Very stressful
- 💬 Maybe it was not appropriate after all for these service users to be at this meeting but I won't allow anyone to consult with my daughter without me being present.
- 💬 These people can be a bit challenging, need structure and routine. They will run rings around them.
- 💬 I don't like the idea of volunteers taking them out in the community. Are they going to have DBS checks?
- 💬 I have two disabled sons. I am worried that I won't be able to do anything anymore. It will stop me going to the Doctors or going to work.
- 💬 If my daughter is at home and is not kept doing something she explodes. She would be up and down the walls driving me crazy with no day centre.
- 💬 He is always at the door waiting for the bus to come. My son would be lost without this place. If he doesn't see the bus coming he starts hitting himself.

How do you feel about the plans for Haringey Adult Social Services? [Based on the responses given in the first question]

Carer – The Roundway



"My daughter was taken out of services for a while. Staff had to call the police because they could not deal with her. If staff who knows her well can't cope how are strangers going to manage?"

- 💬 I do not trust Haringey Council, they are not genuine. They've already decided what they are going to do. I am outraged
- 💬 How can we give you feedback if we do not know what we're consulting on? How can we be consulted on what we do not know about?
- 💬 We have only learnt about what's going on because of the staff. [Only 5 out of 26 people at the meeting said that they had received the proposals.]
- 💬 All the documents I have received have no mention of The Roundway closing. Is the Roundway closing or not? I'm confused? This is confusing and stressful?
- 💬 I did receive the info but I did not understand it and the information given by Haringey Council has not been filtered down.
- 💬 What does Social Enterprise Model mean anyway?
- 💬 Everyday our resident looks forward to the day centre if he don't go he gets stressed.

- 💬 Even if there is an issue of double funding, some people have not been assessed for years.
- 💬 Some people will become socially isolated. At least here they meet different people.
- 💬 Most clients would say yes and no to the same question. So we need to speak up for them. Is this a deprivation of liberty? Haringey are discriminating against those who do not have a voice. They have a vote but most of them can't use it. Get ignored.
- 💬 The Council will end up getting cheap labour and losing good staff.
- 💬 The new Care Act is coming in and support will have to be taken into account as well as the needs of carers.
- 💬 I'll go absolutely doolally!
- 💬 The impact on us as parents will be death! Can't go the Doctors. Can't do anything. The mental strain on us as a parent is bad enough. Places like this maintain our loved ones health and wellbeing as well as ours. I can't see how I can cope. I will run back to Nigeria and leave her here.
- 💬 Time scale is very rushed.

Why do you feel that way about the plans?

- 💬 I live on my own with my daughter. I have hospital appointment. If she is at home with me I can't go because of her stress. She would be up all night.
- 💬 He loves the staff. He loves the day centre. I'd hate to think that Haringey Council will close a place like this.
- 💬 2 areas affect my daughter because of double funding. There is nothing in the community for her. She will not be safe.
- 💬 I am lost for words.
- 💬 The quality of support for these autistic people is being compromised once again.
- 💬 How many times can you take them to the same place? They get bored.
- 💬 These staff know these clients. If other people come along we'll have to start the long process all over again.
- 💬 If this is the strategy of Haringey with such a limited time to consult we as parents cannot do anything about this. We don't get the choice to do anything about this.
- 💬 Personal budgets are not allowing enough money. I don't feel they want to pay enough to support my daughter.

Session 3: Circle of Support, The Roundway Centre

If Haringey Council goes ahead with all their plans ... How would it affect the users of services day to day life?



Circle of Support – The Roundway Centre

“One of our service users used to go to Central. He had a particular routine. He never used to go out and when he did he used to abscond. We used social stories to show him that he was coming to this building. He now understands that he attends the Roundway. He has a set programme when he goes out. He has a named member of staff. He has particular routines which he must complete. He can now explore the local area. It has taken us from September 2013 until now to achieve this. If he feels he is going back or is going to Birkbeck Road he will deteriorate and exhibits challenging behaviour to show that he is not comfortable.”

- 💬 What sort of service will service users get if they are not able to access the day centre? This is a big respite facility for carers and families that enables them to go out and do their jobs and other things.
- 💬 Opportunities during the day are limited. This will have a huge impact on relationships – some service users only trust specific members of staff.
- 💬 Skill levels will go down. Learnt skills over the years will have to be relearnt. It takes time to build relationships most service users here are Autistic. It will be difficult for them to adapt to change especially as they’ve just been through a major one already. They have only just started to really settle down from that. It will affect their behaviour. It is a complete change to their routine. The process will need to be very slow. It will need to be in stages. To move them around again will only confuse them even more.
- 💬 Staff have the impression that day centre will close down and that they will not continue to support the clients. Uncertainty around the meaning of the loss of 96 jobs full time equivalent and that staff will no longer be employed by Haringey Council. Whatever the meaning, it will be a massive change in long term.
- 💬 There are other service users who will abscond if they feel unsafe. They won’t go near dogs or public transport. We don’t have massive community relationships.

How do you feel about the plans for Haringey Adult Social Services? [Based on the responses given in the first question]

- 💬 Anxious and confused due to the vagueness of the proposals. There is an inability of the group to grasp the true concept of the proposals.
- 💬 Staff have been placed in a difficult situation with parent carers.
- 💬 Parents are stressed.

- ☞ This is a serious risk to the service user and their carers.
- ☞ Overall it's difficult to say how we feel if we do not know what effect this will have on services.

Circle of Support – The Roundway

“The impact will not be felt until after the fact. They live in the moment not the future. They are autistic.”



Why do you feel this way about the plans?

- ☞ Don't think impact of the proposals have really been understood by the people making the proposals.
- ☞ Service users have enough challenges in their day to day life as it is. How much stress must they keep on enduring?
- ☞ If we are not around the impact will have to be dealt with by the residential home and the parent carers who may not be equipped or ready for the fall out.

5.6 BIRKBECK ROAD SERVICES

29 users of service at Birkbeck Road were able to speak up for themselves.

Staff and family carers were also identified as 'Circles of Support'. They spoke up on behalf of the users of services too.

Based on the question: If Haringey Council goes ahead with all their plans ... How would it affect your day to day life? We asked people “What does the Day Centre mean to you?”

User of Service – Birkbeck Road

“I enjoy the centre. I look forward to coming here every day. What would I do if I couldn't come here?”



[In the users of services own words and supported by staff]

- ☞ The centre is important.
- ☞ We love coming here.
- ☞ Please don't take it away.
- ☞ We would struggle to get through the day.
- ☞ I would be at home 7 days a week
- ☞ What will we do? Stay at home getting bored senseless?
- ☞ We would be bored not coming here.
- ☞ I think I will have to find a job to go to?

- ☞ Where would I go? Where would we go... nowhere to go?
- ☞ Tired, bored, at home – sleep all day.
- ☞ I do not want to stay at home I want to go to the centre.
- ☞ I would get bored I want to keep the centre open
- ☞ I'd like a job and come to the centre as well as.

Based on the question: How do you feel about the plans for Haringey Adult Social Services? [Based on the responses given in the first question] we asked people “How would it make you feel if the day centre had to change your service?”

User of Service – Birkbeck Road

“We don’t like changes because it’s confusing.”



[In the users of services own words and supported by staff]

- ☞ What’s going to happen?
- ☞ I’m hoping for the best.
- ☞ The worry is upsetting me.
- ☞ I can get money out of my bank – that can help them out?
- ☞ We chose the name of the centre ‘Always’ – we chose ‘Always’ because we thought we would always stay there.
- ☞ LEAVE IT ALONE!
- ☞ I think about the part of not giving anyone enough money to do things
- ☞ It’s bad
- ☞ Angry.
- ☞ I don’t want the centre to be closing. I do like it here I do gardening, bowling, and I work
- ☞ Prefer it here to Roundway. I was at Roundway before.

Based on the question: Why do you feel this way about the plans? We asked people “Why do you feel this way?”

User of Service – Birkbeck Road

“I would be bored doing the same thing every day like shopping.”



[In the users of services own words and supported by staff]

- ☞ I will miss the staff
- ☞ It’s not fair on my carer
- ☞ I’m going to write to David Cameron, he’s the one doing the cut backs. I have written 3 letters.
- ☞ If I stay at home I will be upset
- ☞ Upset and annoyed I will lose my friends and key worker.
- ☞ Means so much to me I would get banners. I would get my friend and a banner to keep it open. I would go to the Civic Centre and protest.

- 💬 They're making cutbacks.
- 💬 I feel like a yoyo. Up and down, up and down?
- 💬 Sad.
- 💬 Angry and sad
- 💬 I'm very disappointed with council.
- 💬 I want it to be open here. I feel horrible.
- 💬 I have had the same staff for a long time
- 💬 When I get off the bus the staff make a cup of tea for us If we have been out in the cold. Helps us get warm
- 💬 The staff help me with my problems.
- 💬 staff help me to cross the road to help me be independent
- 💬 I have had lots of changes. I like it here
- 💬 Staff not just here to do activities they help me with my life. They are important.
- 💬 Staff comforted me when my mum died
- 💬 Staff helped me when I lost my sister. Staff help us in other ways.

Session 2: Carers, Birkbeck Road

Carers joined in the session with users of services. During and after the meeting they also said the following.

Carer – Birkbeck Road



"My son has been in the service since 19 years old? There have been so many changes and threats of changes. We do not know if we are coming or going?"

- 💬 All these changes. My mother in law does not speak English I support her and my sister. They need me to interpret on their behalf.
- 💬 I feel lost I don't know what to do. This is such a horrible feeling.
- 💬 My sister is aging and her mobility needs and care have increased. She's not only disabled, she is also elderly. I have to consider, on a daily basis what activities we do. I need the centre to lighten the load.
- 💬 I do not want them to close this place as my daughter is happy here despite the barriers. She is so happy.
- 💬 In holidays when centre is closed she can't wait for centre to open. She keeps asking.
- 💬 Staff supports us.
- 💬 I call on staff. We speak over the telephone if there is a problem.
- 💬 Who would help us?
- 💬 As a carer when my loved one is at the day centre it gives me time to do the things I need to do.
- 💬 It would tie me down if my sister was at home more. I will not be able to do those things.

Session 3: Circle of Support, Birkbeck Road

A Circle of Support for the users of services at Birkbeck Road also gave the following feedback.

Circle of Support – Birkbeck Road



“To communicate with our clients effectively plans need to be done way in advance. Some of this is not appropriate – some of the information is unacceptable.”

-  We do not know the impact this will have on Service Users until it happens. For those people who are non-verbal you do not know the impact immediately.
-  The day centre is great. It improves behaviour. We facilitate people to make choices. People already have the option of doing other things.
-  Lots of clients will go downhill. Lots of clients have been here between 15 – 25 years.
-  15 months ago people moved from the Roundway to here. People have just settled down.
-  Most of the people who come here are living in residential/ supported living. This is going to reduce the service from 75 people per day to 17 (approx.) If the residential homes don't provide a balanced service people will become deskilled. This will impact on this group the most as they will have to leave.
-  Let's pool resources – club together to get the work done. Get a support worker who can support 3 or 4 of them. There will be no central organisation to do this.
-  Lots of residential homes do not have staff during the day. A lot of the staff don't take part in or focus on personal and social development of the clients. They focus on personal care and cooking. Haringey are trying to save money but are they actually saving money in the long run?
-  For me it seems like going back to the olden days with people sitting at home all day. Clients now mix with people, make friends, do things they want to do. The community isn't all that and people don't want to be out all day, every day. Some people have less mobility than others, may not want to walk, struggle with the cold weather and have challenging behaviour in the community.
-  Our clients keep saying what's going to happen? When is it going to happen? It's confusing to keep on telling people “It's just an idea?” and that there's nothing concrete. However, there are some people who have understood about the changes, the possible closure of day service and the impact on them.



Circle of Support – Birkbeck Road

“Is there is a robust system in place for safeguarding? Is there going to be an auditing procedure to check safeguarding? Without any form of day service many will be feel very vulnerable, isolated and at risk. Many more people will be open to hidden abuse.

- ☞ There seems to be no alternative to the closure of the day service
- ☞ We pick up lots of stuff to support the family. We feed into the Social workers and health teams. Escorts are able to raise the alarm on issues at the home. If someone is just receiving day services we do the review. We chase the reviews. We deal with social, emotional, mental, wellbeing, safety, health, bus passes, blue badges, benefits etc. For some people we are their only point of call.

5.7 GENERAL COMMENTS

LDX has identified below relevant general feedback from users of services, carers, circles of support and stakeholders that was made at different times during corporate and specific consultation sessions.

Service Users – People First

“Society is not accessible or appropriate for people with LD. We are far away from being an inclusive society.”

- ☞ How did you work out the cuts of 30 million?
- ☞ Stop giving financial answers to moral questions. You do not have to prescribe the 3 year plan now. Don't make a stronger Haringey of the weakest people. Wait until after election. Have a holding budget instead.
- ☞ Holiday periods and religious festivals should be avoided when having Council consultation (Government policy).
- ☞ Have political parties considered sharing salaries of top paid counsellors/officers in order to preserve places like Ermine Road?
- ☞ I think this is a sad day. It's a cut down for me. You can go 2 days, you can go 1 day. Haringey loves to be in the news. They love ITV. Haringey is waiting for something to kick off. People with learning disabilities have views but they cannot speak for themselves. Cutting all services means everyone locked up in their homes with nowhere to go. It will be like the little girl Climbie? I can see it happening again. I'm waiting for something to happen after you shut down the day centre. People with learning disabilities may not be able to think straight but leave us alone.

- ☞ Only the mild to moderate can utilise reablement support. Other core groups will not be able to increase burden of care on families. It will be a breakdown of families and services.
- ☞ Older people homes have previously been closed and are now sitting empty. Why can't you re-open them and use them? You've not explored all of the options open to you.
- ☞ Osborne Grove is a health issue. What explorations are being made about beds? The partnership between Health and Social Care is an important issue. Osborne Grove is an important facility to have and we should be working together to get health to fund it.
- ☞ Saving money should be the furthest thought away.
- ☞ What extra services will be put in place?
- ☞ If the day centre closes $\frac{3}{4}$ of the clients will lose friendships overnight. It will have devastating consequence.
- ☞ Accessible, appropriate, safe access life opportunities not often cut by society. Essential in people accessing society.
- ☞ Lots of bad things out there for people with Learning Disabilities. Lots of Hate Crime.
- ☞ Somewhere along the line we need people like Mencap. I've been bullied all my life and my parents died suddenly. They helped me.
- ☞ No one thinks people will be more lonely. It's a vulnerable position to be in. The centre can make a difference.
- ☞ We are very worried as a group about if the day centres are closed. We are the Speak Up group. We say 'No' to cuts. The group holds up our cards to say 'No'.
- ☞ Council responsible for behavior of providers. Difficult line to draw. How are monitoring this?
- ☞ The Council are building a stronger Haringey but not off the backs of the weakest/vulnerable people.

6 OTHER INFORMATION

In addition to the information that LDX has collated, users of services, carers and stakeholders gave us letters, emails, statements and written documents to deliver to Haringey Council about their concerns.

LDX has forwarded these to the named person at Haringey Council.

6.1 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

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