



Review of day centre provision in Haringey for people with learning disabilities

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1. Introduction

Haringey Council is planning to open a day centre for people with learning disabilities in Spring 2020. They commissioned Healthwatch Haringey to carry out research to:

- Understand what a good quality of life looks like for people with learning disabilities and their carers.
- See how day centres can best support people with learning disabilities and their carers to have a good life.
- Identify barriers for people with learning disabilities and their carers which stops them from having a good quality of life.

This research was commissioned by the Lead Commissioner for Adult Learning Disability and Autism and conducted in collaboration with the Severe and Complex Adult Learning Disability (SCALD) reference group. It was carried out between May and November 2019.

2. Executive summary

We visited four day centres and interviewed three managers, two service users and seven carers.

Day centres' strength

The day centres we visited were of a decent size and were accessible and suitable for people with physical and learning disabilities. They had access to safe gardens and open space and offered indoor (art/music, sensory room, cooking/baking, dance/Zumba) and outdoor (bowling, swimming, gym, gardening) activities. These activities were well received by service users. Day centres also offered 1-to-1 and 2-to-1 support, as well as group support.

Day centres' challenges

Interviews with managers revealed issues around funding, staffing and transport. Insufficient funding led to a shortage of full-time suitably trained staff. Additionally, there was high staff turnover and an over reliance on temporary/agency staff which hugely impacted the quality of services.

There was also inappropriate budget planning for service users as key workers were not involved; therefore, service users may not have a budget appropriate for the support they needed.

Transport was another major difficulty. Day centres were challenged by the lack of drivers and/or buses, which could cause delays in pick-up times or lead to cancellations; and there was no alternative transport provided for a contingency.

Service users' experiences

Service users like to spend time with friends and families and enjoy outdoor and indoor activities. They have a choice and are involved in planning their activities and their timetable. Service users explained they did not like any sudden changes to plans or activities, such as an alteration in the pick-up time or of a key worker.

Carers' experiences

Carers would like to have time that fulfils their needs and their children's' (people with learning disabilities) needs. Carers could have their routines while they are sure their children are safe and happy at day centres. They are involved in planning their children's activities and advocate for them. Delays or cancellations to transport or a change of key worker presents a problem for carers since this can trigger challenging behaviours in service users which is difficult for carers to handle.

Recommendations

Recommendations have been developed based on the data we collected from visiting day centres, interviews with service users/carers and a focus group with carers.

Transport: There should be more buses/drivers so transport would be on-time and cancellations would be avoided. It is also recommended to have a preferred supplier list of taxi companies with appropriate cars for people with physical disabilities that carers or day centres could use if their regular transport did not arrive. Additionally, the use of alternative transport, such as shared taxis, taxi apps or Com cabs, should be considered. Service users could have travel training or travel buddies if needed.

Staffing: Day centres would benefit from more full-time staff with relevant training (e.g. challenging behaviour, autism). Day centres should offer career development opportunities and better salaries, thereby improving retention rates. Day centre should use less short-term temporary agency staff.

Budgets: Budget planning should involve key workers, families/carers and social services in order to have the best outcome for service users. Moreover, budget plans should be more inclusive (e.g. include respite in care package).

Support for carers: Day centres should provide training for carers (e.g. relevant to challenging behaviours, communication skills) besides exercise and other social events which could also serve as a platform for carers to exchange ideas and information. Longer opening hours could be another way in which to provide support to carers (especially when the pick-up time was delayed).

Building: It is important the day centre's building plan accommodates physical and communal activities (e.g. dancing) as well as activities promoting independence and domestic skills (e.g. training kitchens). These activities were popular among service users at day centres we visited. The building should be autism appropriate with a sensory room/environment, as the sensory room was mentioned as one of the most popular indoor activities. The physical environment should be robust enough to withstand abuse or challenging behaviours.

General:

- Day centres should work with external experts such as The National Autistic Society and The Challenging Behaviour Foundation, as these could provide relevant training for staff and have the expertise to carry out inspections.
- There should be monitoring and assessment of the quality of staff and services through a regular inspection regime, including on the spot visits.
- Centres specifically for autism could better accommodate the needs of autistic service users.
- Day centres should have integrated health services on-site (doctors, nurses, dentists, therapists). They should also offer additional services such as dieticians (eat healthy at day centre, healthy cooking at home).
- Planning for people with learning disabilities should be outcome focused, focusing on what they can do rather than what they can't do (a strengths-based approach).

It is important social services have a comprehensive understanding of the complex needs of people with learning disabilities.

3. Methodology

Our literature review highlighted that well-being was a key concept in this research, and so we used 'Five ways to well-being', proposed by the New Economic Foundation, as the framework to this research:

- Being in control of life: socialise, learn new things.
- Have a voice: involved in planning activities.
- Staying safe: abuse elimination.
- Personal care: help to be independent.
- Having a full life: get to know local communities, flexible services.

This research was qualitative in nature. A qualitative approach is most appropriate if the research objectives are to learn from the participants in a setting or a process by the way *they* experience it, the meaning they put on it and how they interpret what they experience.

Qualitative research provided rich, deep and detailed data and made it possible to build up an understanding of service users/carers' feeling and experiences.

Observation, semi-structured interviews and focus groups were employed as the data collection techniques.

We visited three day centres in Haringey and one day centre in Barnet. The SCALD Reference Group visited two day centres in Camden and Islington to review of best practice.

Also, semi-structured interviews were conducted with:

- Three managers at day centres
- Two service users with mild learning disabilities
- Seven carers/advocates of people with severe learning disabilities.

Interviews were conducted by Healthwatch Haringey's research associate.

Prior to the interviews, the researcher read various academic articles and case studies in order to prepare the right set of questions and approach. The questions were consulted on with representatives of the SCALD reference group and informed by their feedback.

Interviewees were selected based on two factors:

- Fit within the criteria: service users with mild or moderate learning disabilities, service users with severe learning disabilities and/or their carers

- Their willingness to participate in the research and their availability within the time period of the research.

Interviews were conducted at a time and place convenient to participants.

Interviewees with mild learning disabilities were accompanied by a key worker at day centres. All interviewees were given an information sheet explaining the purpose of this research, how the data is going to be used and stored and their right to withdraw at any time. Their consent was gained after providing information and answering their questions and before the interview.

The data was analysed by the researcher and the main themes identified. The initial findings were presented at the SCALD meeting followed by a focus group. The final findings include the feedback form the focus group.

4. Findings

Day Centres: Overview

The following day centres were visited by Healthwatch Haringey:

- Ermine road: purpose built
- HAIL and Centre 404: within community centre
- DALO: within fitness centre

They were accessible from main street, side street or from the park entrance. They all had activities for people with moderate to severe learning disabilities and people on the autism spectrum. Activities were led by staff and/or staff + people with learning disabilities.

HAIL did not have activities for people with mild learning disabilities.

DALO and Ermine road offer some activities for people with learning disabilities and their carers/families. Ermine road offers advocacy for carers and a Carers Forum, once a month.

Centre 404 has First Aid training as well as Sign Language training for staff. They all had general Health and Safety training for staff as well as protocols to report incidents (documentation, monitoring, take further actions if needed).

SCALD visited two day centres in Islington (Daylight Spectrum) and Camden (Greenwood Centre) and Table 1 presents a comparison of day centres in Haringey and those outside the borough.

Table 1: Comparison of day centres

| Similarities | Differences |
|---|---|
| Services for people with profound and multiple disabilities and/or autistic spectrum | Strong link with families, engagement of the service with families of service users (Daylight Spectrum) |
| A purpose-built space (similar to Ermine Road) | Outcome focused, try to meet the identified needs of an individual so they develop new skills (Daylight Spectrum) |
| A community at the centre, stronger connections with the local community (similar to Centre 404 and HAIL) | Offers information, advice and support from social workers, nurses, doctors and other therapists |
| Access to outdoor space with facilities for gardening | Involves health team (e.g. speech and language therapist, dieticians, community nurse) in planning, delivering and evaluation |
| A range of activities (on-site and off-site) | More flexible with personal budget |

Three day centre managers were interviewed to capture good practice and challenges.

Day Centres: Challenges

Staffing

Two of three managers mentioned shortage of staff as a major problem;

“Funding is insufficient for full-time staff. Staff who bring service users from residential or care homes are casual...they may have just started working. Casual staff managed by different managers; however, ideally manager of a day centre should manage them.”

“We used to have nurse and medical staff which was helpful, don’t have anymore...we have the problem of staffing around holiday seasons or if one or two staff get sick.”

Transport

All three managers stated that lack of drivers/buses is an issue which could affect the pick-up time or even end in cancellation.

“Dial and ride not always gets customer on-time. Customers may not be able to attend if they rely on normal taxi companies.”

“When we don’t have enough drivers we need to prioritise, priority is for carers who go to work.”

Budget

Lack of funding which could lead to lack of staffing was discussed as a difficulty besides inappropriate funding as there is no involvement of key workers in personal budget planning of service users.

“Council wants customers to benefit from being in the community/community centre but for less money.”

“It would be better if we could be involved in customers’ budget planning. For example, some customers have group budget support but they actually need 1-to-1 support.”

Service Users

Two service users with mild learning disabilities were interviewed as well as seven carers of service users with severe learning disabilities and/or challenging behaviour and autism, as representatives of their children.

What matters most?

Service users would like to spend time with family and friends and they enjoy outdoor and indoor activities. Service users know their way around day centres and have a bond with key workers and other service users. Key workers and staff know their likes and dislikes.

“I come here two days a week...I like baking and floristry...”

“My son doesn’t have friends outside day centre. He sees key workers and other service users as his friends. He wakes up every morning gets dressed and waits for transportation because he is excited to see his friends.”

“My son is very happy to go to day centre. He is waiting for bus even days with carer he puts on cloths waiting to go out. He likes cooking and art sessions. He is calm when he comes back.”

Service users or their carers have a choice and are involved in planning their activities and timetable. Activities are diverse and good for both the physical and mental health

of service users. Sensory rooms, bowling and gardening were mentioned most as their favourite activities.

“I don’t like music carpet, I like sensory room. I told Paul (hey carer) to take me for swimming.”

“There are activities that interest my son, he is not forced to do anything he doesn’t like, so his challenging behaviour won’t begin.”

“I know what my son likes, I cooperate with his key worker to include his favourite activities.”

What makes them anxious?

People with learning disabilities dislike sudden changes to plans or activities. Delays in pick-ups or cancellations or changes of key workers were all mentioned as examples of sudden change.

“My daughter goes to activities like Zumba and singing. If I had to keep her at home she lashes out, slams the door and gets anxious.”

“He doesn’t like his routine to change, he needs to be informed in advance. I have to repeat a few times for him to understand any change of activities or staff which makes him nervous.”

“Seeing key workers and other service users makes my daughter clam. If she doesn’t go for example because bus didn’t come, it triggers her challenging behaviours.”

Carers

Carers not only represented their children but also talked about their experiences.

What matters most?

It is very important for carers to have time that fulfils both their needs and their children’s need. It is also important that their children (people with learning disabilities and/or autism) are safe and are offered activities that make them happy.

“Good week is when he goes to day centre. I have time to run errands. He enjoys going to day centre or going out with his support worker and I can book appointments.”

“My life was disturbed when her usual day centre closed, it was difficult for her to adapt to new routine. I couldn’t leave her alone for a second, I was about to have a nervous breakdown.”

“Him being at day centre is a rest time for me. Day centre gives him a structured day and I can socialise, do shopping and go to meetings.”

What are the issues?

Any sudden change in plan/activities/key workers, delay or cancellation of transport and an unsafe environment for children are major issues that carers have to deal with.

“I wouldn’t change anything; my son doesn’t like it. He likes his key worker and even the time that bus picks him up is important.”

“His day centre didn’t change since six years ago. He likes stability. Pick up time couldn’t change; it will make him very upset.”

“Upon closure of her usual day centre she went to supported accommodation and she had an incident (they shaved her hair) which affected both of us. I couldn’t trust them and had to take care of her at home before being referred to another day centre.”

“I visited a few centres and respite before choosing one. I wanted to choose one that has a safe and friendly environment.”

The issues with transport (delay or cancellation) have particularly significant impacts: it will trigger challenging behaviours in service users which is difficult for carers to handle; and carers have to cancel their appointments and rescheduling is not always easy.

What could change?

Carers suggested some changes and improvements that would be of great help for them;

- Longer opening hours

“Pick up time doesn’t need to change but drop off could be later than 4.30pm.”

“Sometimes the bus comes late in the morning but they still come back at 4.30pm. I can’t manage to do my stuff.”

- Support for carers

“We always have to employ people because we don’t have training for practical matters.”

“Day centres could provide us training how to handle challenging behaviours.”

“We get along as usual, don’t know exactly how to understand our children. If we had training, we could communicate better.”

“It would be good if there were activities for us too, like exercise session. We could talk to each other, exchange ideas and generally socialise too.”

- Centres specifically for autistic service users

“The previous centre she was going, was autism centre; this one is a mixed centre. In specific centre they teach them because they can learn.”

“My son doesn’t like to be in groups, in the autism centre where he used to go they had sessions adapted for him.”

The following recommendations were discussed in the focus group:

- Day centres to work together with external experts such as The National Autistic Society and The Challenging Behaviour Foundation, for inspection or training.
- Regular monitoring and assessment of the quality of staff and services to take place (on the spot visits).
- Use of alternative travel (e.g. shared taxis, taxi apps) or having travel training/travel buddies which enhances the confidence of service users too.
- Day centres to have integrated health services on-site (doctors, nurses, dentists, therapists). People with learning disabilities are calm and more cooperative at day centres and it would be helpful to have check-ups or screening.
- Day centres to offer additional services such as dieticians (eat healthy at day centres, healthy cooking at home).
- Outcome focused planning for people with learning disabilities, focus on what they can do rather than what they can’t do (a strengths-based approach).
- Make sure that building accommodates physical and communal activities (e.g. dancing) as well as activities promoting independence and domestic skills (e.g. training kitchen).
- Make sure a sensory room/environment is included in the building as it has been mentioned as the most popular indoor activity.
- Make sure social services have a comprehensive understanding of the complex needs of people with learning disabilities.

The Ideal Day Centre

To summarise, the findings of this research suggest the characteristics of an ideal day centre are as follows:

- Accessible, decent size, safe buildings to be a low arousal environment, neutral colours and special lighting.
- Access to safe outdoor space/garden.
- Offer mix of indoor and outdoor activities that are good for physical and mental health.
- Has adequate full-time staff with relevant training and good retention rates.
- Offers support for carers.
- Have integrated health services in planning, delivery and evaluation.

5. Limitations

The limitations of the research are as follows:

- Small sample size: This is due to limited time and budget. We aimed to complete the research by December 2019 so Haringey Council could see our findings and incorporate these into their designs for the new day centre. Accessing service users/their carers and gaining their agreement to participate in the research was a delicate and time-consuming task. Furthermore, arranging for interviews was difficult given the tight timetable of the research and the busy schedule of carers/service users. There were also cases where interviews were cancelled on the day because transport had been cancelled and carers could not make the appointment. On a general note, transcribing more interviews and observation notes takes a level of staffing which was beyond this research budget.
- Limited number of interviews with service users: This is due to two reasons: a) limited access to service users with mild or moderate learning disabilities who were verbally communicative and would like to participate in the research; b) carers did not want for their children to be present at the interviews. They stated that their children will be stressed and/or be a distraction to carers.

It would be possible to overcome these limitations if there was a bigger budget and more time for Healthwatch Haringey to reach out to a larger sample group.

However, despite these limitations, the interviews we carried out with service users and carers elicited a wealth of information, so we had some very rich data to draw on and work with.

6. Appendices

Appendix I: Info sheet

In spring 2020, a day centre for people with autism and learning disabilities and their families will be opening in Haringey.

Healthwatch Haringey in collaboration with the Sever and Complex Autism and Learning Disability Group (SCALD) will be carrying out research to hear from people with learning disabilities and their families. We want to know how people would like to use the day centres and what barriers would need to be removed for them to be able to go there and benefit fully from activities and services.

We are looking for people aged 18 and above with a learning disability for which they receive social care support from Haringey Council, as well as one or more of their family carers, to take part in this research.

If you choose to be involved, we will:

- Arrange a time and place to meet you and your relative for a face-to-face conversation focused on the needs and preferences of the learning disabled person.
- Arrange a separate time (either face-to-face or over the phone) to speak to you about your needs and preferences as a carer.
- Share the final research findings with you in autumn 2019.

Interviews can take place at a time and location where you and the person you are caring for feel most comfortable. We will work to involve people with all levels of disability in the research as fully as possible, though we realise that some people with more severe learning disabilities may need a family member or support worker to speak up on their behalf.

If you would be interested in sharing your views or know someone who you would like to help to take part, please contact **Maryam Hamedi, Researcher at Healthwatch Haringey** on **research@publicvoice.london** or **020 8888 0579** for an initial chat and to arrange a time for a longer face-to-face interview.

Who are Healthwatch Haringey?

Healthwatch Haringey is an independent consumer champion for everyone using health and care services in Haringey. We use what we hear from local residents to influence and improve NHS and care services so that they work better for everyone. Healthwatch Haringey is run by Public Voice (CIC), a social enterprise based in Tottenham.

Who are the SCALD?

The Severe, Complex, Autism and Learning Disability Group (SCALD) are carers who represent the interests of service users with complex needs. The members meet bi-monthly as a Reference Group and highlight issues relating to the quality of and access to health and social care services in Haringey. The Reference Group nominates two representatives to the Haringey Adult Social Care Joint Partnership Board.

Appendix II: Consent form

Healthwatch Haringey, managed by Public Voice (CIC), in collaboration with the Sever and Complex Autism and Learning Disability Group (SCALD) will be carrying out research to hear from people with learning disabilities and their families. We want to know how people would like to use the day centres and what barriers would need to be removed for them to be able to go there and benefit fully from activities and services.

Consent:

The data collected in this survey is anonymous and will be stored safely and securely by Healthwatch Haringey. In order to help improve services, we may use your anonymous information in a final report to Haringey Council.

Please tick here if you **do not want** your anonymous data to be shared.

Consent part (2):

Your basic personal details (name and contact) will be shared with Healthwatch Haringey should you agree to have further discussion/interview.

Please tick here if you are happy for us to share your information as detailed above and Healthwatch Haringey to contact you.

Print name:

Date:

Signature

Appendix III: Interview questions

Main questions:

What matters most during the week?

What makes a week a good week?

Who would you like to spend time with?

Where do you/service user feel safe/less anxious?

What makes service user feel unsafe/anxious?

What do you/service user like to do in your spare time?

Do you feel that you get the chance to live the life you want?

What helps you live the life you want? Activity? Leisure time.

What makes it hard to live the life you want?

If you could change one thing?

What do you want to stay the same?

What do you want in a day centre?

Supporting questions:

Do you feel you have a choice and can control your life?

How day centre helped you or could help you to exercise choice?

How easy is it for you to communicate your feelings/opinions?

How day centre helped you or could help you to expand your network and communicate better?

Appendix IV: Day centre visit check list

| | |
|--------------------|--|
| Name of the centre | |
| Date | |

Building

Is it purpose built? Yes No

Is it easily accessible? Yes No

If it is not purpose built, is it suitable for activities and offered services?

Decent size Enough rooms Enough signs

Additional comments

.....

.....

If it is not suitable, what is the problem?

Overcrowded

Not suitable for people with multiple physical and learning disabilities

Not enough space for people with different needs

Additional comments

.....

.....

There is access to outdoor space and/or garden? Yes No

The building feels safe for disabled people. Yes No

Staffing

There is enough number of staff. Yes No

There is staff to support one to one support/activity. Yes No

There is a health team at the centre.

Physiotherapist Speech and language therapist Occupational therapist

- Community nurse Psychologist
- Any other healthcare professional

Additional comments

.....

.....

Activities and services

What on-site activities/services are offered?

.....

.....

What outside activities/services are offered?

.....

.....

There are activities tailored to the needs of disabled people? Yes No

Activities are flexible with personal budget. Yes No

There are choice of activities for:

- people with mild learning disabilities
- people with moderate learning disabilities
- people with severe learning disabilities
- people with multiple physical and learning disabilities
- people within autism spectrum
- people with disabilities and their carer/families.

Who leads activities?

- disabled people
- disabled people and staff
- disabled people and carers/families

carers/families and staff

staff

Is there a chance for disabled people and/or their carers/families to meet peers and develop a network? Yes No

Additional comments

.....

.....

Any training offered for disabled people?

.....

.....

Any advice offered to disabled people and/or their carers/families?

.....

.....

General comments:

.....

.....