

Autism Residents Advisory Group (ARAG) Meeting Stratford Advice Arcade 06/10/2025 10:00am – 12:00pm

Attendees: Emma Akosua – Co-Chair, Resident Rep Linda Wan – Co-Chair, LBN Commissioner Daniel Nichols – LBN Commissioning Assistant (minutes) Patricia Moody – Support Facilitator, VoiceAbility Aisha Ahmed – Senior Peer Support Worker, ELFT Christina Pillau – ASDB Co-Chair, Resident Rep Tia Barnes – LBN, SAIL Team +3 online Residents/Guests +8 in-person Residents/Participants	Guest Speakers: David Bryce – NHS, NEL ICB Paul Evans – LBN, Homelessness Commissioner Elizabeth Owen – LBN, Public Health Matt Bury – LBN, Public Health
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Item	Note / Action agreed	Action by
	These minutes should be read alongside the accompanying slides	
1	Welcome, introductions/apologies and meeting rules Emma (Co-chair) welcomed everyone to the meeting and explained the purpose of the group. She then outlined the meeting rules.	
2	Autism and Homelessness David and Paul presented: - As both support services and wider society become more aware of neurodivergence, it's prevalence, and potential impact on our lives, there is a need to shine a light on the intersection between autism and homelessness. - Recent research conducted by Oxford University suggests that 12.3% of people experiencing homelessness are autistic, compared with 1-2% of the general population. - Why is this the case, and what can we do about it? - They began by speaking to professionals at all levels across London and England to better understand their approaches and ways of creating pathways of support for autistic adults within a complex and often hard to navigate system. - They heard from commissioners and frontline practitioners alike, hearing about their successes and challenges, alongside hearing about the journeys of the people they supported. - They knew we needed to hear from a wider pool of professionals to truly measure the scale and depth of work needed. They distributed a survey designed to capture the challenges, alongside examples of good practice, that professionals who worked with those experiencing homelessness in London were facing, and their experiences navigating the system. Their survey found that: - There needs to be greater recognition and awareness of the prevalence, presentation, and support needs for autistic people (and for those experiencing co-occurring autism and homelessness), coupled with nuanced understanding of the spiky profile of needs and presentations.	

2. Flexibility and accommodation of autism should be adopted within services, both in the environment and in interactions with practitioners.
3. Changes to services should be co-produced with autistic people.
4. Gender-informed approaches should be embedded within services to increase understanding of women's experiences of autism and homelessness.
5. There is a need for commissioners and funders to better understand the needs of autistic people, thereby improving the identification of, and commissioning for appropriate outcomes.
6. There must be structural changes to pathways for support, including access to rapid and flexible diagnostic assessments, specialist open ended support and resources, preventative support, amendments to priority need and statutory duties, and appropriate accommodation and pathways.
7. We need a joined-up approach throughout the system – there should be joint working and sharing of information between services, and pooled funding.
8. Recurrent in-person training must be implemented for all staff about autism and homelessness.

They then presented a case study of TS who was neurodiverse, had a learning disability and multiple brain injuries. He had been in and out of prison for many years and found engaging with probation and services to be difficult.

Initially he would be picked up by a care navigator from Pentonville Prison and taken to probation and other services. However, he kept disappearing and being recalled to prison for failing to comply with bail conditions, usually after having an alcohol induced fit and being hospitalised.

Following liver health and Speech and Language assessments, more insights were gained into his history and diagnosis. It was found that he had an IQ of 60 and would often pretend to understand things that he did not. These assessments helped to secure a care package for his multiple physical and mental health needs and guidelines for working with him. For instance:

- Using words and pictures to convey an idea.
- Breaking things into smaller steps and simplifying plans as much as possible.
- Not speaking in sentences with more than two clauses.

After episodes of bullying and abuse at his initial care home placement (one of which led to him being hospitalised and going into a coma), he was eventually found a more suitable placement. Although he sadly died at the end of 2022, he had recently celebrated his first full year out of prison in decades.

Access to Assessment in Newham:

- Work began in Newham to provide access to rapid and flexible diagnostic assessment for people experiencing homelessness.
- Meetings took place involving professionals of different specialisms and looked at ways we could streamline the referral process for diagnostic assessment.
- In Newham we have 21 people who have been rough sleeping in the borough for a long period of time due to multiple disadvantages. This flexible approach would give those with undiagnosed autism access to an assessment.

	• If autism is diagnosed, this would give the practitioners a better understanding on how to work with the rough sleeper and support with pathways off the street. • One of the main reasons for homeless is eviction from previous properties. The meeting was then asked the following questions: 1. Does anyone know of someone autistic that has lost their accommodation and/or become homeless? a. If so, how did they resolve it? b. If so, were they rough sleeping, put in TA, etc? 2. Does anyone know what to do to contact the council about losing their tenancy? a. How would they help? 3. Has anyone received help/support to maintain their tenancy? a. How did they help and did they resolve your problem? b. How helpful did you find these? 4. Have you ever felt like you could lose your home? a. And for what reason did you think you might? In response to these questions, the residents made the following points: • Problems with the amount of time that it can take to get an assessment for autism. • Problems getting Educational, Health and Care Plans (EHCPs) in place for people at school or college post-diagnosis. • Lack of reasonable adjustments from schools and colleges. • One person had personal experience of homelessness and living in Bed & Breakfast (B&B) accommodation after an eviction. The project aims to help people who are evicted and end up in B&Bs or other forms of temporary accommodation. • Problems around transitioning from child to adult care.	
4	Barriers to Vaccination Elizabeth and Matt presented. They explained that they are both public health professionals who respond to outbreaks of infectious diseases. They are currently working on increasing the uptake of flu vaccinations. Some groups of people (such as carers and people with learning difficulties) get vaccinations for free but uptake is currently low for people with learning difficulties (under 30%). They asked the group why some people are hesitant about being vaccinated. The issues raised by the group were: • Bad reactions to previous vaccinations. • Needle phobia • Having to have the COVID and Flu vaccinations. • Worries around consent and record keeping. In response, Elizabeth and Matt said that: • Those with needle phobia can choose to have their vaccination by nasal spray. • The eligibility for COVID vaccinations is a lot narrower currently than in previous years and you can opt to take flu and COVID vaccinations on separate days. • All vaccinations are voluntary.	

5	Minutes and matters arising The minutes of the last meeting were approved. All the actions were completed with the following exceptions: • The consultation on the merger of the autism diagnostic services in Newham, Tower Hamlets and City & Hackney hasn't started yet (see Governance Board updates below). • Natalya's action is still outstanding (below). Action 1: Natalya to share information on "Uniting Friends" Talking Therapies.	Natalya
4	Governance Board Updates <u>Linda Wan – Autism Delivery Board</u> • Papyrus Suicide & Autism Professionals Training – additional SPEAK training 23 Oct & 2 Dec 2025. 2-day ASIST training held 25/26 Sept. • Autism Working Groups to restart shortly with newly appointed Resident Experts • The Trust are currently looking at merging the services of the three boroughs in their patch (Newham, City & Hackney and Tower Hamlets) into one, the Newham service will remain open until April. The consultation on this hasn't started yet. • Jason McCulloch presented on Newham's Supported Accommodation Strategy: ○ The strategy looks at the next 10 years. ○ Gaps in provision identified for: Autism-specific services; Complex needs; and Floating support. ○ Newham is working on a more enabling approach to transitions and looking at the 14+ and 16+ cohorts. There were no updates from the Health & Care Partnership Board or the Health & Wellbeing Board. Due to changes in board memberships and reporting criteria there is currently no upward reporting to these boards. We are currently in the process of identifying representatives on these boards to provide feedback on the Autism Programme. Linda mentioned a series of videos that have been made by the Met Police to provide information for neurodiverse people as an example of a project that could have benefitted from ARAG members feedback that was missed due to our lack of representation on the above boards. This sparked a discussion on the way that autistic people are treated by the police and the broader justice system. Linda responded that Superintendent Lucky Singh would be attending the Open Surgery at the Stratford Advice Arcade on Friday 28th November to discuss these issues. Members can book a slot by emailing autism.commissioning@newham.gov.uk Action 2: Linda to invite Supt. Singh to a future ARAG meeting.	Linda
5	Autism Action Plan – progress on actions	

Experts by Experience 2025/26

Linda explained that there are 10 Expert by Experience (EbE) roles. EbEs are paid for attending the committees that they sit on. After a vote was held for the P3 role, she announced the new EbEs for 2025/26:

1	ASDB Co-chair	Christina Pillai
2	ARAG Co-chair	Emma Akousa (interim until successor found)
3	Carers Rep	Sue Sinton Smith (interim until successor found)
4	Young Persons' Rep (18-25)	vacant
5	P1 (Improving understanding & acceptance of autism)	Sarha Heba (New)
6	P2 (Improving autistic children & young peoples' access to education and transition)	vacant
7	P3 (Supporting more autistic people into employment)	Catarina Horta Bargao (elected by ARAG members)
8	P4 (Tackling health & care inequalities)	Jay Gee
9	P5 (Building the right support in the community & support inpatient care)	vacant
10	P6 (Improving support within the criminal & youth justice systems)	vacant

The above vacancies will remain open until they are filled. More information on them and details on how to apply are available at [expert-resident-role-descriptions-2025](#)

Newham Autism Small Grants Funding

The Autism Small Grants will enable local autistic residents to build community resilience by applying for one-off funding of up to £1,000 to:

- support the costs of running activities on a regular basis, and enabling new activities to set up;
- support the costs of running groups meeting on a regular basis, and enabling new groups to set up.

The grant funding will remain available until all the monies are spent. Visit [Newham Autism Action Plan: Let's Talk Autism – Autism – Newham Council](#) for more detail on how to apply.

AccessAble

AccessAble have a contract with Newham to provide online accessibility guide for venues, shops and other public places in Newham. You can find the guides at [Home](#) | [AccessAble](#)

Their contract is due for renewal next year and Newham would like them to provide information for autistic people in their guides going forward. Aisha has drawn up the following list of factors, gathered from ARAG members and other autistic residents, for them to consider in their assessments -

Accessible environments:

	• Have a designated quiet space- sensory friendly • Autism hour- less busy period • Bright lights -dim lights/sunglasses available • Noise- reduce/no background music/use headphones • Crowds and queues- fast track entry to bypass queues • Temperature- adaptable temperatures • Maps- travel to the destination/within the building itself • Prepare a sensory/social story (A Social Story's aim is to improve the child or adult's understanding by simply sharing social information. With improved social understanding clarity and predictability is established and anxiety is diminished). • Relaxed performances: Theatres, cinema and other venues that offer live entertainment could offer specific performances or screenings that are autism friendly. Sensory Environment • Smells: Avoid strong, overwhelming scents from air fresheners or cleaning products. • Visuals: Minimize clutter, distracting patterns, and overwhelming visual information. Use calm, consistent colours and clear imagery. Any further factors that members think should be considered in these assessments should be sent to autism.commissioning@newham.org.uk Elizabeth asked if there would be any opportunities for ARAG members to be paid to do these assessments. Linda said that she would raise this with the company. Action 3: Linda to look at obtaining paid opportunities for ARAG members to conduct autistic accessibility assessments. <u>Peer Support Video</u> Aisha is leading on producing a 'how to' video on setting up peer support groups.	Linda
6	Any Other Business It was remarked that the rules on mobile phone usage during the meetings need to be looked at again.	
7	Dates of future meetings Monday 26th January 2026, 10am-12pm, John Hopkins Room, Stratford Library (Speaker Topic - Supported Accommodation Strategy)	