

Autism Residents Advisory Group Meeting Stratford Library 27/01/2025 10:00am –12:00pm

<p>Attendees: Emma Akosua – Co-Chair, Resident Rep Linda Wan – Co-Chair, LBN Commissioner Daniel Nichols – LBN Commissioning Assistant (minutes) Patricia Moody – VoiceAbility, Support Facilitator Aisha Ahmed – Senior Peer Support Worker, ELFT Christina Pillau – ASDB Co-Chair, Resident Rep Shantell Thomas – P1 Lead, Expert by Experience Natalya Fisher – P2 Lead, Expert by Experience</p> <p>+8 online Residents/Guests +12 in-person Residents/Participants</p>	<p>Apologies: 1 x resident</p>
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Item	Note / Action agreed	Action by
	These minutes should be read alongside the accompanying slides	
1	<p>Welcome and introductions/apologies</p> <p>Linda welcomed everyone to the meeting and explained the purpose of the group. Emma (Co-chair) introduced herself and explained the meeting rules.</p>	
2	<p>Guest Speakers</p> <p>1. <u>Manchester University (Kelly Birtwell, Laura Brown & Erin Beeston)</u> Kelly, Laura and Erin presented findings from their research on autistic adults’ perspectives on ageing and some information on their ongoing research projects. They then outlined the aims of their presentation and the questions that they wanted the group to consider. They stated that there has been very little research into ageing as an autistic person and this led to difficulties providing appropriate information, support and services. They aimed to explore and understand autistic adults’ perspective and concerns regarding ageing and how to age well.</p> <p>They then gave details of their sample and methodology for their interviews with older autistic people and outlined the research findings. The study found that:</p> <ul style="list-style-type: none"> • Autistic people experienced interactions between their autism and physical ageing and wanted to know if being autistic increased the risk of age-related illness; • It was also found that autism made it more difficult to adopt preventative health behaviours; • Some aspects of autism became more challenging with age; • Some people reported changes in their ability to ‘mask’ autistic characteristics; • Some people were concerned about changes in caring responsibilities; 	

- Autistic people felt they had smaller social support networks throughout life and often relied a lot on support from family members;
- People felt that being autistic put them at greater risk of social isolation in later life;
- Autistic people wanted more knowledge about ageing with autism and struggled to find older autistic 'role models';
- People felt that there should be more knowledge and understanding of autism within services;
- Some characteristics of autism made it harder to access support and many health & social care services are currently not suitable for autistic people.

They then outlined the details of the sample and methodology that they had used for another study which surveyed autistic adults. The study found that:

- Factors considered important in doing well in old age were support for independent and autonomous living from people with a good level of knowledge of autism and social/digital inclusion;
- The participants were worried about losing their independence and autonomy, non-informed health and care staff & services, conditions like dementia and menopause and isolation & a lack of support.

The conclusions from the study were that:

- There is an urgent need for more knowledge and education about the age-related needs and experiences of autistic people;
- Health and social care services need to be designed to better meet the needs of autistic people;
- If you design or deliver services (of any kind), try to involve autistic people in the design and delivery of these services;
- Inclusivity and adjustments tend to benefit everyone.

There is an ongoing **study into GP support** for autistic adults. Its preliminary conclusions are that autistic people often delay seeking support from GPs and fear being judged negatively by practice staff for doing so. This could increase anxiety and stigma and lead to a negative cycle where treatment and support are delayed, and outcomes worsened. They are therefore seeking to create guidance for both GP staff and autistic people on this matter. They are also setting up an interdisciplinary network of researchers, professionals and volunteers to improve autistic adult' access to research and collaborate on grant applications.

Autism & Health inequalities research

- peer support communities – especially for late diagnosed adults - are effective at creating space for people to come to terms with their new identities, foster a collective sense of belonging and provide space for individuals to re-frame traumatic experiences.

A discussion then took place amongst the group about Autism & health inequalities.

Issues raised included:

	<ul style="list-style-type: none"> • Socio-economic barriers to autistic health (the researchers said that this had come up in other studies); • The lack of data in the study from people from ethnic communities and the specific barriers that they face; • The lack of understanding from social prescribers. There was agreement that more research was needed for prescribers, link workers and peer supporters. <p>(see slides for details)</p> <p>Linda thanked the researchers for their input and highlighted Aisha’s work to set up peer support groups and a pilot proposal for a “buddy” system for autistic residents to access an escort to appointments and such for moral support.</p> <p>2. <u>Healthwatch Newham (Manushi)</u> Manushi presented, saying that there was a lower uptake of cancer screening amongst autistic people due to the aforementioned barriers to healthcare that they experience. They are therefore holding focus groups on bowel and breast cancer screening on the 29th and 30th January 2025 at Canning Town library to look into the issues further. Participants will receive a £10 shopping voucher.</p>	
<p>3</p>	<p>Minutes and Matters Arising</p> <p>16 people participated at the last meeting. Its theme was education and training. It was shared by a participant that there are bursaries available for autistic students in higher education and that University of East London do a lot to support people with additional needs.</p> <p><u>Actions</u></p> <ol style="list-style-type: none"> 1. Linda and Kirsten still working together to identify training needs. 2. Linda to share the summary from Shantell ‘s work 3. Linda to share priority leads’ email addresses. 	
<p>4</p>	<p>Governance Board Updates</p> <p>1. <u>Strategic Delivery Board (Christina)</u></p> <ul style="list-style-type: none"> • London Fire Brigade gave an update on the work that they are doing on improving fire safety for autistic people in the borough. • There is a new autism page on the NHS ELFT website https://www.elft.nhs.uk/adult-autism-diagnostic-services • A new suicide prevention strategy for Newham Council (see slides). • Residents are now able to self-refer for eating disorders, a new question has been included to ask if you are autistic. Community Disordered Eating Team (Adults) Referral form East London NHS Foundation Trust • Referrals for autistic homeless people are now fast tracked to the autism service. • The Met Police are engaging with schools to teach children about safety. 	

	<p>2. <u>Autism & Learning Disability Joint Planning Board</u> No report as October meeting was cancelled.</p> <p>3. <u>Health and Care Planning Board (Emma)</u> Emma made a presentation to the board on her journey to an autism diagnosis. She described problems that she had with her GP and with social communication.</p>	
5	<p>Autism Action Plan: Experts by Experience – progress on actions</p> <p><u>Priority 1 - Improve understanding and acceptance of autism within society (Shantell Thomas)</u></p> <ul style="list-style-type: none"> • Work ongoing to make services in Newham more autism friendly. • Oliver McGowan training is being rolled out across the health sector in North East London. <p><u>Priority 2 - Improve autistic children and young people’s access to education - and support positive transitions into adulthood (Natalya Fisher)</u></p> <ul style="list-style-type: none"> • Working with Raj Mistry from LB Newham Children and Young People’s service on developmental milestones and preparation for adulthood. • Getting helpful books on the subject from a friend who works for the library service. <p>No reports from other priority leads.</p> <p><u>Autism Lead Update – Linda Wan</u></p> <ul style="list-style-type: none"> • World Autism Acceptance Week is taking place from the 2nd-8th April 2025. A calendar of events is being organised. • Anyone interested in becoming an “Autism Champion” should email autism.commissioning@newham.gov.uk • LB Newham webpages updated, encourage all to take a look: Support & Information for Autistic Residents – Autism – Newham Council and Newham Autism Action Plan – Autism – Newham Council (Autism Action Plan & Actions Y1). • Papyrus are organising a Suicide & Autism pilot training session for March. <p><u>Peer Support Worker Update – Aisha Ahmed</u></p> <ul style="list-style-type: none"> • An autism resource pack and monthly autism newsletters can now be found on LBN webpages – see above. • A free 4week cooking course arranged over January with 13 local autistic people taking part • A poetry and origami sessions for autism acceptance week. • A survey on peer support needs will be shared shortly • A peer support group will be piloted in February: Autistic, working and managing work related anxieties. 	
6	Any Other Business	

	<ul style="list-style-type: none"> • A participant shared that they have been appointed as an advisory board for NHS England. • Beckton Library friendship club continues to meet every other Saturday. See Friendship Club on Saturdays Events Newham Libraries • Trish mentioned her drop-in sessions at Chargeable Lane. See VoiceAbility Speak Out Newham • Emma reviewed the meeting rules. A participant pointed out that acronyms were being used too frequently in meetings. 	
<p>9</p>	<p>Date of next meeting</p> <p>Monday 28th April 2025, 10am-12pm, Stratford Advice Arcade</p>	