

Autism Residents Advisory Group (ARAG) Meeting Stratford Library 11/05/2026 10:00am –12:00pm

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| <p>Attendees: Daniel Findlay – Co-Chair, Resident Rep Linda Wan – Co-Chair, LBN Commissioner Daniel Nichols – LBN Commissioning Assistant (minutes) Tia Barnes - LBN, SAIL Team Trish Moody - VoiceAbility</p> <p>+7 online Residents/Guests +11 in-person Residents/Participants</p> | <p>Guest Speakers: Grainne Fennell – LBN LCIS Jason McCulloch - LBN Senior Commissioner Dr Kelly Birtwell – Manchester University</p> |
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| Item | Note / Action agreed | Action by |
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| | These minutes should be read alongside the accompanying slides | |
| 1 | <p>Welcome, introductions/apologies and meeting rules</p> <p>Daniel F welcomed everyone to the meeting and set out the meeting rules.</p> | |
| 2 | <p>Support for Parents & Children in Newham</p> <p>Grainne Fennell from LCIS (Language, Communication and Interaction Service) presented. She is a speech therapist and is part of a team that also includes specialist teachers and other professionals that supports autistic children in mainstream schools and nurseries. They also support parents and carers. The service is free of charge.</p> <p>They offer training courses for parents which consists of four sessions per year. It is available online or in person. Their main offer is in support and training for teachers.</p> <p>Full details of the LCIS offer (including digital copies of the leaflets that Grainne distributed at the meeting) are available here</p> <p>A discussion then took place around the issue of support for parents with school aged children that covered areas such as autism awareness and planning at SENCOs, the problem of undiagnosed autism in parents and the need for training around rights for parents and children.</p> <p>Linda pointed out that Lorna Fry, the head of SEND in Newham, attended a recent Open Surgery and is due to attend further surgeries in the future. In addition to the drop in service offered by the LCIS Team, Parents have an opportunity to access a senior member of staff if they have concerns with their child at school through the Open Surgeries which compliments this offer.</p> | |
| 3 | <p>Manchester University Research: GP analysis</p> <p>Dr Kelly Birtwell presented her research. She explained that her work is a review of literature that had already been published on the subject rather than being primary research. The aim of the research is to understand how, why, and when general practice best supports (or not) autistic adults, with and without learning disabilities, throughout the lifespan.</p> | |

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| | <p>The background to the research is that, compared to non-autistic adults, autistic adults:</p> <ul style="list-style-type: none"> • Have higher rates of health conditions (e.g. cancer, heart disease, epilepsy); • Experience greater unmet healthcare needs; • Face more barriers to accessing general practice; • Report lower satisfaction with healthcare. <p>The literature review was theory driven, involved stakeholders throughout and consisted of six stages that were worked through iteratively. They then set out to develop an initial programme theory (IPT) of how general practice works (or doesn't) for autistic adults. It developed through stakeholder discussions, scoping searches, team knowledge and then mapped the following patient pathway:</p> <ul style="list-style-type: none"> ➤ Identifying a problem ➤ Deciding to seek help ➤ Obtaining an appointment ➤ Getting to the appointment ➤ General practice interaction ➤ Post-appointment & supporting long term outcomes <p>They found that:</p> <ul style="list-style-type: none"> • if autistic individuals have had previous poor experiences of healthcare, where their needs have not been understood or met, they may avoid or delay seeking help, because they feel they won't be taken seriously or believed; • if the healthcare system is not designed to meet the needs of autistic individuals, they may try to self-manage their health, because they feel appropriate support is lacking. <p>Dr Birtwell asked the meeting if these findings make sense and if they seemed familiar or were they surprising. She also asked if anything else came to mind regarding the results.</p> <p>She further mentioned that the assistant reviewers had raised concerns around:</p> <ul style="list-style-type: none"> • Lack of diverse participants; poor reporting of demographic characteristics in research; poor reporting of demographic characteristics in general practice • Treating autistic people with or without learning disability as one homogenous group/ no consideration of different care needs. • People's experiences being invalidated. <p>In the discussion that followed the presentation, concerns were raised that similar problems may apply to secondary care and that there were further problems being experienced by those who had English as a second language.</p> <p>The paper is available here and a supplemental file of information is available here You can contact Dr Birtwell with feedback on the paper at kelly.birtwell@manchester.ac.uk</p> | |
| 4 | Supported Accommodation Strategy – resident consultation | |

Jason presented. He said that Newham Council has to write and publish a Supported Accommodation Strategy by the end of March 2027. The strategy will cover lots of different client groups, including:

- Older Adults
- Mental Health
- Learning Disability and Autism
- Care Leavers
- Single Vulnerable Homeless & Rough Sleeping

The council wants to make sure that Newham residents have a say in the things that the strategy will say it needs to do.

The challenges that the council will face in the coming years include:

- A growing population
- More older people who are frail or are living with dementia
- More people with complex needs including autistic people with learning disabilities, mental health problems and/or physical disabilities
- Rising costs
- Attracting people to work in social care.

The council wants to support people to live as independently as possible and therefore wants to develop services that will support people to:

- recognise their strengths
- develop their skills
- have more control over their lives
- make choices about how and where they live.

The Council wants to ensure that there are enough of the right type of services in Newham so that people don't have to move out of the borough. They will work with residents to understand what they want and will work with partners to make sure people are being supported to achieve their outcomes.

Jason then asked the meeting to respond to some question on the strategy (available in the strategy questionnaire which you can access and respond to [here](#)).

In the discussion that followed a question was asked regarding people being in temporary housing for more than two years. Jason replied that the council needs to get the pathways right for residents in that sort of accommodation and that two years can be an artificial threshold. There was also a question around how quickly new accommodation can be built Jason replied that it may be possible to turn some care homes into supported living accommodation and that the council is hoping to get access to parts of new builds and regeneration projects. The problem of reasonable adjustments being made for people in supported accommodation was also raised and it was pointed out that these should be made regardless of whether or not the person is Care Act eligible.

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| <p>5</p> | <p>Minutes and Matters Arising</p> <p>Linda updated on the previous meeting. She said that Sebastian is still looking for volunteers for his IMPACT project on the experiences of LGBTQ people accessing adult social care in Newham. Volunteers will receive a payment of £27.50 per hour for 1-2-1 conversations (online or in-person). Please email Sebastian at s.j.buser@bham.ac.uk if you are interested.</p> | |
| <p>6</p> | <p>YSTWD 2025/6 & Y3 Priorities</p> <p>Linda presented slides outlining the Autism Action Plan priorities for year 3. The new priorities are:</p> <p>P1: IMPROVE UNDERSTANDING AND ACCEPTANCE OF AUTISM IN NEWHAM</p> <ul style="list-style-type: none"> • Co-deliver autism training for the Council’s operational Social Care Teams, Housing Teams, and in-borough commissioned Care Providers to develop a consistent baseline of understanding and approach. • Establish a local Community Leaders Steering Group to identify the most effective ways to educate and inform Newham’s diverse global community about autism. <p>P2: IMPROVE AUTISTIC CHILDREN AND YOUNG PEOPLE’S ACCESS TO EDUCATION - AND SUPPORT POSITIVE TRANSITIONS INTO ADULTHOOD</p> <ul style="list-style-type: none"> • Embed autism-inclusive early identification and support within Best Start in Life (BSIL) and Family Hub delivery, ensuring children aged 0–5 and their families can access timely, joined-up support. • Strengthen inclusive practice across mainstream education settings by embedding an “Experts at Hand” model, enabling earlier identification and support for autistic children and young people without reliance on statutory assessment. • Develop a coordinated 0–25 transition pathway for autistic young people, ensuring multi-agency planning and earlier preparation for adulthood in line with the local SEND Reform Plan. <p>P3: SUPPORTING MORE AUTISTIC PEOPLE INTO EMPLOYMENT</p> <ul style="list-style-type: none"> • Improve job retention outcomes for autistic residents by providing targeted support to both resident and employer, ensuring appropriate workplace adjustments and increasing employer awareness of autism. • In partnership with local businesses, create Insight Days for autistic young people aged 14+, enabling them to experience ‘real-world’ work environments – to build confidence, develop workplace understanding, and support smoother transition into future employment. • In partnership with the DWP, in-borough secondary schools and colleges, deliver on-campus roadshows, talks, and advice surgeries that familiarise autistic students with employment support services available in Newham. <p>P4: TACKLE HEALTH AND CARE INEQUALITIES FOR AUTISTIC PEOPLE</p> <ul style="list-style-type: none"> • Review information and support available to residents’ awaiting diagnosis and their Carers. Assess impact and consider recommendations for improving the current offer. | |

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| | <ul style="list-style-type: none"> • Improve awareness, accessibility and uptake of existing services that support physical health, mental wellbeing and preventative care (e.g. healthy eating, exercise, cancer screening, etc). • Prevent unnecessary medication through effective delivery of health programs such as STOMP. <p>P5: BUILD THE RIGHT SUPPORT IN THE COMMUNITY AND SUPPORT PEOPLE IN INPATIENT CARE</p> <ul style="list-style-type: none"> • Better understand the reasons preventing discharges from in-patient settings and put in place plans to address these. • Confirm commissioning intentions and timelines for delivering community-based services that will prevent admission and support discharge (e.g. floating support, supported accommodation for residents with complex needs and behaviours). <p>P6: IMPROVE SUPPORT WITHIN THE CRIMINAL AND YOUTH JUSTICE SYSTEMS</p> <ul style="list-style-type: none"> • Work in partnership with the Council-commissioned Appropriate Adult Service to obtain data on the number of autistic people supported, broken down by their protected characteristics. • Arrange autism awareness and neuro-affirming training for employees working across the Family Hubs and Leaving Care Team, so they are better equipped to understand and support young autistic residents. Recognising that Care Leavers and children in need often face a range of life challenges and systemic barriers that may increase the likelihood of them encountering the Youth Justice Service, as either a victim or perpetrator of crime. <p>Action: Linda agreed to look into the question of flags for autism in NHS patient records under P4 & P5.</p> | Linda |
| 7 | <p>AOB Details on forthcoming events included in the slides.</p> | |
| 8 | <p>Dates of future meetings</p> <p>Monday 6th July 2026 10am-12pm Monday 5th October 2026 10am-12pm Monday 25th January 2027 10am-12pm</p> <p>John Hopkins Room Stratford Library (in-person and online)</p> | |