**Autism Residents’ Advisory Group (ARAG) Meeting**

**Parsons Room, Canning Town Library**

**23/05/2023 10:00am – 11:30am**

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| **Attendees:** Linda Wan     (Chair)Daniel Nichols (Minutes)Jason PatelPushpa Patel (Carer)David TaylorKathy Taylor (Carer)Sarifa PatelSatwinder Kaur (PA)Habiba KhanomSerena Elstub | Sally Wood (eastway care staff)Leanne Joscelyne (eastway care staff)Leonardo BecklesManzur SobhanNenka KocheuaMuhammed SohailRichrd Henry**Apologies:** |

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| **Item** | **Note / Action agreed** | **Action by** |
| **1** | **Welcome and introductions/apologies** Linda welcomed attendees to the first meeting. Attendees completed a round of introductions.  |  |
|  | Reminded everyone to complete the sign-up form and photo consent form and clarified the eligibility for this group:* 18+ years of age and
* has a formal diagnosis or
* on the waiting list for a diagnosis with the Autism Diagnostic Service
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| **2** | **Fire Safety**No fire evacuation planned; the designated fire assembly point: Rathbone Market between the large trees |  |
| **3** | **ARAG Ground Rules**Ground rules agreed by all. (See power point slides) |  |
| **4** | **Why are we meeting today?** |  |
| **4.1** | ARAG launchThis is the first meeting for this newly formed group. A minimum of 2w notice agreed for all ARAG meetings.The group agreed to retain the title of Autism Residents’ Advisory Group and agreed use of the acronym ARAG, pending any future recommendation for an appropriate name change. The ARAG would normally have four meetings a year, but acknowledged we will be meeting more regularly this year to co-produce the new Autism Strategy. |  |
| **4.2** | Governance structureThe new governance structure was discussed with the group and diagram shared on the slides. Oversight of the Autism Strategy would be through monitoring of the action plans from the ARAG, Autism Strategy Delivery Group (ASDB) and Joint Planning Group (JPG). Both the ARAG and ASDB will have a resident Co-Chair representation. Concern was expressed about the mixture of responsibilities in the “Adult Learning Disability and Autism Joint Planning Group” as combining the two groups hadn’t worked in the past.In response, members were advised the new governance structure has now created a separate Learning Disability and Autism group to ensure voices are being heard; the ARAG and the ASDB. In addition to this there are co-chair representation at the ARAG & ASDB groups which will feed up to the JPG which will then feed back down to the respective groups. |  |
| **4.3** | Co-chair roleSlides to explain the co-chair role and how to apply was shared.There are two Co-Chair roles available, these can't be the same person and holds a maximum 12month term – ARAG & ASDB. All Co-Chairs must have an autism diagnosis and both the Co-Chairs must be a member of the ARAG. The roles could be done under a ‘job share’ arrangement and is a paid role. The Co-Chairs will be paid for their work at London Living Wage rates. More details for this role will be shared.It was emphasised that the Co-Chair’s written statement should be a *maximum* of 600 words and that support would be provided if needed. |  |
| **4.4** | Newham all-age Autism StrategyThe strategy will be the first All-Ages Autism Strategy for Newham.The strategy will mirror the national strategy with the same six priorities:P.1 improving understanding and acceptance of autism within societyP.2 improving autistic children and young people’s access to education, and supporting positive transitions into adulthoodP.3 supporting more autistic people into employmentP.4 tackling health and care inequalities for autistic peopleP.5 building the right support in the community and supporting people in inpatient careP.6 improving support within the criminal and youth justice systems |  |
|  | A general discussion identified some gaps in the system that can be captured in the action plan including: * GPs need better understanding of Autism and appointments need to be longer. The issue has been raised previously. The process of booking the appointments needs to be simplified too. Telephone appointments are often inadequate as they don’t pick up non-verbal communication;
* Hospitals have similar problems;
* autistic children are excluded from school requiring better support;
* care packages shouldn’t be replaced be educational packages in such circumstances as they are fundamentally different things.
* The meeting also raised the issues of transition from primary to secondary
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|  | Linda agreed to flag these points to children’s services & include in the action plan as part of future discussions with the ARAG priorities workshop. | LW |
| **5** | **What happens next?**We will cover two of the priorities from the proposed strategy at the next three meetings. P1 & P4 were voted to be addressed at the next meeting.Priority 1 - Improve understanding and acceptance of autism in Newham and Priority 4 - Tackle health and care inequalities for autistic people |  |
| **6** | **AOB**Feedback form – all to please complete  |  |
| **7** | **Next Meeting**tbc |  |