

Principles for engaging, involving and consulting autistic residents in Hackney

The engagement and consultation work stream of the Autism Alliance Partnership Board drafted the following principles, adopted by the board.

1. Autistic representation on the Autism Alliance Partnership Board

- The board should aim for a proportion of at least 25% of autistic representatives to balance the board, this should be in addition to parent/carer reps
- The board needs more autistic people than parent-carers to ensure focus on primary experience of autistic people
- Representation should reflect diversity representation from women and residents from Hackney's Black and Minority Ethnic communities and people with different levels of support need
- There is a need for a local user-led group/forum or network of autistic residents to ensure representatives are accountable to others
- Current board terms of reference allow for a co-chair; the co-chair should be an autistic resident
- A young autistic representative would be desirable – at the very least on the service planning/transition work stream
- Autistic representatives and carers on the board should be remunerated for their attendance in line with the principles of equity and fairness. Most/all board members will attend as part of their paid job
- Autistic people should be represented on all the work streams/groups linked to the board

2. Accessible meetings (including work stream meetings, board meetings and any meetings held as part of the formal consultation process)

Meetings need to be autism-friendly and accessible and should include the following:

- Flexibility to enable 10 minute 'time out' if autistic reps become overwhelmed
- Flexibility to suspend meeting and restart again – not continue the meeting autistic person's absence – this is a reasonable adjustment
- No neon/fluorescent light, natural or full spectrum light if necessary
- Quiet room/space provided for the time out
- No requirement for autistic representative to socialise before or after meetings
- Documents provided well in advance including easy read if needed
- Easy read materials developed explaining what the board is for, doing and how autistic people can be involved
- Timed agenda items to reduce anxiety – with flexibility for 'time out' if needed

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- An opportunity to provide a briefing to non-autistic board reps on autism and what makes an accessible board meeting
- Ensure judgements are not made re lack of eye contact during the meeting
- Communication methods must meet the communication needs of the representatives, these may differ and may include some reps submitting written rather than verbal contributions to discussions
- All meeting documents and language used in meetings to be non-ambiguous/plain speaking/jargon free, for example do not use 'apologies' use 'apologies for absence'
- Decision making and other processes at the board to be clearly explained and adhered to
- Language and terminology used in reports and paperwork should be respectful and reflect identify first preferences (autistic not 'with autism', suffering from' or 'ASD', see <http://aut.sagepub.com/content/20/4/442.abstract>)
- Please refrain from using highly scented products such as perfumes and aftershaves (lightly scented soap and deodorant is fine) and remove smoking smells before joining the meeting
- Meetings to take place in venues/rooms with minimal exposure to excessive environmental noise including traffic noise or smells

3. Consultation

- The formal consultation on the strategy should take account of the range of communication needs of autistic people and be adapted and designed to ensure maximum engagement of local autistic people
- This may include consulting via a range of social media channels, a dedicated secure web page, providing easy read questionnaires in person and by post, running accessible consultation session and visiting autism day centres/hubs (eg Church Walk) and local supported housing units
- Recognition of and provision for autistic people with complex communication needs would need additional professional support to share their views

4. Additional suggestions

- Autistic board representatives would welcome the opportunity to lead reviews of existing services from an autistic perspective
- Any training should include 'user led' training – led by an autistic trainer – there are plenty of experienced trainers to choose from
- A generic email 'Autism in Hackney' email address would be helpful as long as it is monitored and tells people how long it will take to respond as would a dedicated web page on the Council site.