

# AUTISTIC RESIDENT ADVISORY GROUP (ARAG)

Tuesday 30 April 2024

**Chair:** Serena Elstub, ASDB Resident Representative  
Linda Wan, Autism Lead - Commissioner

# AGENDA

1	Welcome & Introductions <ul style="list-style-type: none"><li>- Meeting Rules</li><li>- Autism Strategy Launch Summary</li><li>- Video 6m19s</li></ul>	Linda Wan, Council Co-Chair	10.00-10.10	10min
2	Guest Speakers <ul style="list-style-type: none"><li>i-NHS, Hospital People Participation Leads</li><li>ii- Our Newham</li><li>iii- Accessible Housing Design (on-line)</li></ul>	Mbemba Bojang & Anna Sandiford Sharleen Ferrol Fulgence & Ervina McCulloch Jan Healey & Marney Walker	10.10-10.25 10.25-10.45 10.45-11.05	10min 20min 20min
3	Minutes & Matters Arising (14 Nov 2023)	Linda Wan, Council Co-Chair	11.05-11.10	5min
4	Autism Strategy Delivery Board (ASDB) <ul style="list-style-type: none"><li>- Updates (20 Feb 2024)</li></ul>	Sabrina Bafli, ASDB Co-Chair	11.10-11.15	5min
5	Autism Strategy, what's next? <ul style="list-style-type: none"><li>- Action planning</li></ul>	Linda Wan, Council Co-Chair	11.15-11.25	10min
6	AOB		11.25-11.30	5min

# Meeting Rules

Linda Wan



**Please speak slowly with easy words**



**No jargon to be used**



**Stop if people show they don't understand**



**Use you communication cards if you want to speak**

# Meeting Rules

Linda Wan



**please give us a chance to ask questions**



**make sure everyone has time to understand what is Being said**



**Don`t speak over each other**

# AUTISM STRATEGY LAUNCH

# Autism Strategy Launch

Linda Wan



1. **>140 participants**
2. **Presenters:** NHS England, London Autism Lead, PWC, Auticon, John Lewis, Trainer/Coach, Hopeful Futures...& more
3. **Business vacancies/Jobs Fair:** Retail, Care, Training & Service industry
4. **All-age Autism Strategy** available to download or view shortly [Newham All-Age Autism Strategy – Autism – Newham Council](#)
5. **Newham Autism Video** [https://youtu.be/0xfxQj\\_ipQc](https://youtu.be/0xfxQj_ipQc)





# Autism Strategy Launch

Linda Wan



[newham.gov.uk](http://newham.gov.uk)

**WE ARE NEWHAM.**

# **BARTS HEALTH NHS TRUST People Participation Service**



# NHS, Hospital People Participation Team

Mbemba Bojang



## What is People Participation?

People Participation offer support and training for Newham Hospital service users and carers who wish to be actively involved in Barts Health continuous improvement agenda.



# NHS, Hospital People Participation Team

Mbemba Bojang



## What do we do?

- We recruit Patient representatives for Newham Hospital Working Together Group

“Putting engagement and participation at the heart of improving experience”

- We offer support and training for Newham Hospital service users and carers who wish to be actively involved in Barts Health continuous improvement agenda.
- We engage and listen to Newham resident, our patients and carers. We work with them to make sure we deliver what they want. That’s why your voice is so important.



[newham.gov.uk](http://newham.gov.uk)

**NHS**  
Barts Health  
NHS Trust

**WE ARE NEWHAM.**

# NHS, Hospital People Participation Team

Mbemba Bojang



## WORKING TOGETHER GROUP

- This provides a meaningful platform for Newham Hospital service users and carers to be actively involved in the hospital's continuous improvement agenda.

## Key Activities

- World café hospital event
- 15 steps challenges



**Barts Health**  
NHS Trust

# NHS, Hospital People Participation Team

Mbemba Bojang



## Who can be involved from the community?

- Anyone living in Newham and who has used the Newham hospital services within the last 12 months
- Carers of those who have used the hospital services within the last month
- Inpatients and outpatients
- Community hospital services i.e. Birth centre and diabetic clinics





# NHS, Hospital People Participation Team



Mbemba Bojang

World Café as a forum for brainstorming and idea generation.



- Looking for a mix of 10 autistic residents and carers
- Wednesday 25 September 9-12pm at the Hospital – Autism Themed discussion



# NHS, Hospital People Participation Team

Mbemba Bojang



## Get in touch

### **Mbemba Bojang:**

People Participation Lead

07861759139

[mbemba.bojang@nhs.net](mailto:mbemba.bojang@nhs.net)

### **Anna Sandiford:**

People Participation Lead

07751 675 963

[anna.sandiford@nhs.net](mailto:anna.sandiford@nhs.net)



**Barts Health**  
NHS Trust



# SUPPORTING AUTISTIC RESIDENTS

## Our Newham Team

Tuesday 30<sup>th</sup> April 2024

Sharleen Ferrol-Fulgence  
Ervina McCulloch

**Our Newham** brings together services that support residents into training, employment, promote their financial wellbeing, and support local businesses.



# Our Newham Money



- Hardship Fund
- Debt Advice
- Benefit & Income Maximisation
- Money Management
- Affordable Credit
- Employment Rights Hub



# Our Newham Money

## Smart Spending



## Benefit and Income Advice



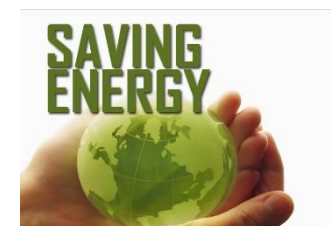
## Debt Advice



## Budgeting



## Energy Advice



# Employment Rights Hub

In the UK there are laws that protect you at work. These laws mean that your employer must treat you fairly. If your employer does not, then they may be breaking the law.

## About the service:

- Free and confidential
- Available exclusively to Newham residents
- Easily accessible
- Information, advice, guidance and support
- 1-2-1 access to an experienced adviser
- Bespoke workshops to upskill residents



# Employment Rights Hub

Some of the issues we can support include:

- Rights when you lose your job
- Working hours and conditions
- Taking time off work
- Asking for reasonable adjustments
- Being treated fairly and equally
- Issues with pay
- Rights for families and parents
- Mental well-being
- Trade unions
- Discrimination

**Contact the team:**

✉ [employmentrights@newham.gov.uk](mailto:employmentrights@newham.gov.uk)

☎ 0203 373 6494

Mon-Fri 9am-5pm



# Contact us



Work

Money

020 3373 1101

[ournewhamwork.engagementteam@newham.gov.uk](mailto:ournewhamwork.engagementteam@newham.gov.uk)

[www.ournewhamwork.co.uk](http://www.ournewhamwork.co.uk)

0208 430 2041

[Ournewhammoney@newham.gov.uk](mailto:Ournewhammoney@newham.gov.uk)

[www.ournewhammoney.co.uk](http://www.ournewhammoney.co.uk)

[www.newham.gov.uk](http://www.newham.gov.uk)

Visit us

112-118 The Grove

London

E15 1NS

# DESIGNING A WORKSHOP TO SUPPORT AUTISTIC RESIDENTS

# Our Newham Workshop



- Pre employment support
- Job matching
- In work support
- Disability Inclusion Policy
- Apprenticeship and supported employment programmes
- Work placement experience



- Hardship Fund
- Debt Advice
- Benefit & Income Maximisation
- Money Management
- Affordable Credit
- Employment Rights Hub

# Accessible Housing Design

Jan Healy & Marney Walker

# Accessible Housing Design (on-line)

Jan Healy & Marney Walker



**Housing Design for neurodivergent residents and residents with learning disabilities**

# Accessible Housing Design (on-line)

Jan Healy & Marney Walker



## The OT Service

Rachel Russell, Marney Walker and Jan Healey are Associate OTs with the OT Service, an independent company that is working with Newham on this project

Between us we have many years of experience and knowledge of housing and housing design including supporting people with adaptations to their homes

Newham have asked us to conduct this study to better understand the housing design needs of residents who are neurodivergent, residents with autism, residents with learning disabilities and their families



# Accessible Housing Design (on-line)

Jan Healy & Marney Walker



## Key aims and outputs:

- To produce an evidence-base of the Housing design needs of neurodivergent residents and residents with autism
- To co-produce a 'Housing Design guide' with key stakeholders to promote better-designed housing for residents

# Accessible Housing Design (on-line)

Jan Healy & Marney Walker



## 1. Stakeholder engagement

- Conducting workshops with a range of professionals and services that support and work with these residents
- Attending resident advisory groups to hear their experiences and views about the housing design needs of this population
- Visiting new build developments and regeneration projects

# Accessible Housing Design (on-line)

Jan Healy & Marney Walker



## 2. Collaborating with key stakeholders

- Focus groups and interviews will be conducted to explore what the key housing design needs are for these residents
- Collecting data on design needs from residents, families, care and support services, agencies and professionals
- Co-production of a housing design guide for residents who are neurodivergent and residents with autism

# Accessible Housing Design (on-line)

Jan Healy & Marney Walker



## What are your housing design needs?

- In your experience :
  - what aspects of the design of your home works well ?
  - what aspects of the design are a challenge?
- **Space and Layout**
- **Safety and Security**
- **Acoustics**
- **Lighting**
- **Access to outdoors**

# Accessible Housing Design (on-line)

Jan Healy & Marney Walker



- In your experience, how does the design of you home impact on your:
  - Health and Well-being
  - Reliance on care and support
  - Access to Employment
  - Opportunities for social interaction
  - Engagement in the wider community

# Accessible Housing Design (on-line)

Jan Healy & Marney Walker



- Of all the housing design features mentioned today, what would you say are the **most** important factors and why?
- Is there anything else you would like to say about housing design for residents who are neurodivergent and residents with autism that hasn't been mentioned?



# Accessible Housing Design (on-line)

Jan Healy & Marney Walker



Thank you for sharing your views and experiences with us.

If you would like to be involved in the next stages of this project, please contact Claire Laurence – Principal Planner:

**[Claire.Laurence@newham.gov.uk](mailto:Claire.Laurence@newham.gov.uk)**

# Minutes & Matters Arising ARAG

# Minutes & Matters Arising

Linda Wan

## Autism Residents' Advisory Group (ARAG) Meeting

Canning Town Library, Elizabeth Fry Room

14/11/2023 10:00am – 11:30am



Co-Chair Linda Wan

Co-Chair serena Elstub

Daniel Nichols

Public health team – Anne Bowers

Employment team Joseph Kunyeda

11 attendees face to face

5 attendees online

1 carer

~~VoiceAbility~~- Trish Moody, Abbie Palmer

Attendance sheet

Photo consent

Welcome, introductions, rules of the meeting

# Minutes & Matters Arising

Linda Wan



## Autism Residents' Advisory Group (ARAG) Meeting

Canning Town Library, Elizabeth Fry Room

14/11/2023 10:00am – 11:30am

Joseph Kunyeda presentation – employment

- CV support
- Build work experience
- Job taster
- Paid employment
- Work with employers too raise disability awareness and training for staff support people with additional needs to stay in employment with Reasonable adjustments
- they are on the end of the phone to support with any difficulties such as Mental health
- Job coach will stay in place throughout employment
- access to work a government funded programme is also available
- 18-25 yrs. Supported internship which is 10 months training eg John Lewis supports people to work in different departments of John Lewis it helps with experience CV is more structured, and the stigma is disappearing throughout John Lewis company
- Supports with employment rights
- Financial and Debt management benefit support
- They want people to work and for them to be better off
- There is a form to fill in you can just walk into the building and do

# Minutes & Matters Arising

Linda Wan

## Autism Residents' Advisory Group (ARAG) Meeting

Canning Town Library, Elizabeth Fry Room

14/11/2023 10:00am – 11:30am

Anne Bowers came and talked to the group about the work she does with public health

- 50 steps to a healthier Newham, health and well being strategy
- Public health work with the population not 1 to 1
- Meaningful actions across the wider determinants of health and well being
- Supporting communities to improve health and wellbeing
- Act as an advocacy tool for policies that promote health equality in Newham and beyond
- Newham has no real input to Climate change



# Minutes & Matters Arising

Linda Wan



## Autism Residents' Advisory Group (ARAG) Meeting

Canning Town Library, Elizabeth Fry Room

14/11/2023 10:00am – 11:30am

### Voices of attendees

- Doctors receptionist – they aren't aware of the need to have more patients receptionist reaction to autistic people can cause conflict
- There needs to be a support service when contacting GPs
- More Face to Face GP appointments
- Preventing you getting help in the first place (doctors)
- Mental health experience long waits
- Local swimming centre won't take cash only card – “how can I stay healthy if they don't except my money”
- Cash Activist – need exploring

# Autism Strategy Delivery Board Update ASDB

# Autism Strategy Delivery Board (ASDB)

Linda Wan



- **Autism Strategy Update:** Linda shared progress and tasks for refining the strategy.
- **April Autism Launch:** Linda detailed an employment-themed event planned for April 18th.
- **Children's Services:** Julie discussed CYP's strategy journey and upcoming role changes.
- **Autism Updates:** Updates included Joint Planning Group activities, ARAG focus groups, and a new Peer Support Worker role.



# Autism Strategy - Next Steps

## ASDB

# Autism Strategy – next steps

Linda Wan

- **ARAG meetings**
  - i) quarterly
  - ii) guest speakers
  - iii) Feedback from working groups: Monitoring, oversight & challenge on action plan
- **ARAG member roles**
  - i) oversight on progress made on action plan
  - ii) voluntary roles in action plan
  - iii) paid roles in action plan – outcome and output focused
- **Strategy to be finalised and shared shortly**
  - i) opportunities to get involved in delivery of the strategy (see above)

**AOB**

- Carers of Autistic Residents Peer Support Group

to access informal support advice and guidance from likeminded people and help shape services. Register here [Carers of Autistic Adults Register \(jotform.com\)](https://www.jotform.com)

- University of 3<sup>rd</sup> Age (U3A) - new group for Newham residents

u3a is a UK-wide movement of locally-run interest groups mainly for people aged 50 and over, it gives opportunities for people to come together to share their talents and learn for fun. Members explore new ideas, skills and activities together for example if you are good at gardening, you can share this in the group. If you are interested, please contact:

**Peter by text or WhatsApp: 07514 154 573**



### Carers Peer Support Group

**Do you care for or support an autistic adult as a parent, unpaid carer or friend?**

Join our new group to share information, give and receive support and make new friends, as well as helping to shape the All Age Newham Autism Strategy.

**Date:** First Wednesday of each month,

**Time:** 11.00am - 1.00pm

**Where:** Community Room, Morrison's,  
Canning Town, Silvertown Way,  
London E16 1ED  
Parking below the store

Coffee and tea provided.

For more information or to confirm your attendance, please contact  
Sue Sinton Smith [suesintonsmith@hotmail.com](mailto:suesintonsmith@hotmail.com) 07968424738 (text only)

**To find Morrison's:** cross the road from Canning Town Station and go straight ahead, past cafés. Morrison's is on the left after Superdrug.

The Community Room is on the right, after the flower stall.

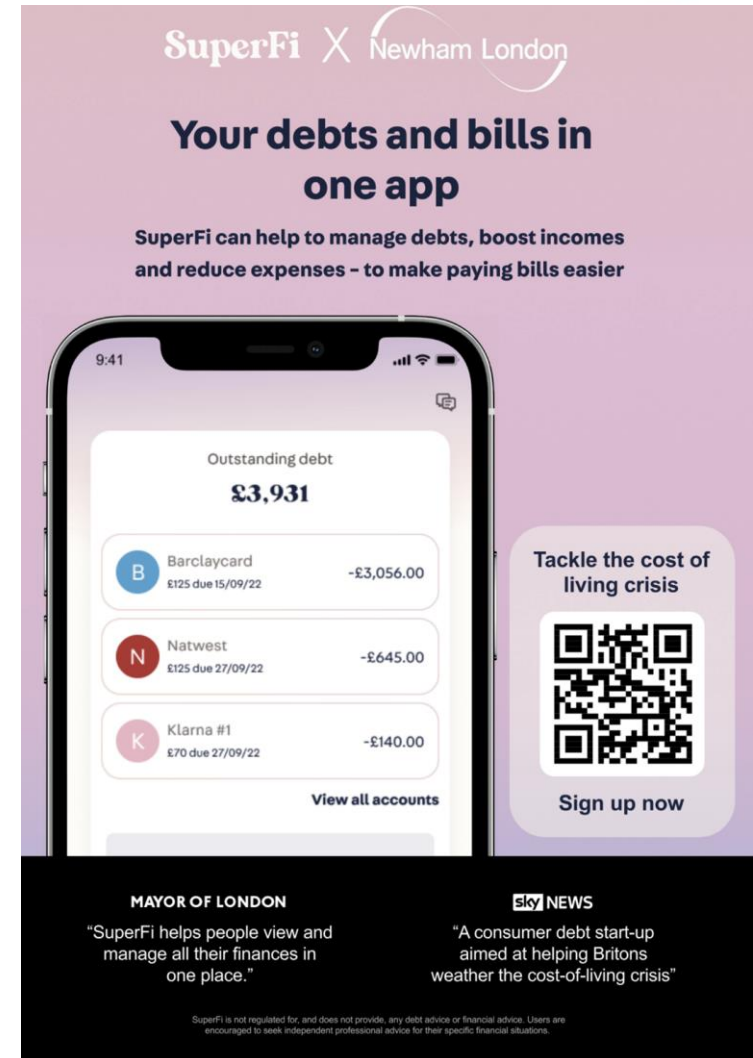
- ARAG Co-Chair Role

- **SuperFi** Free app to manage bills & debt;

From receiving reminders on your monthly bills (such as Council Tax or utilities), accessing discounts from your favourite retailers, easily viewing and/or cancelling your subscriptions to even checking if you're receiving all of the government benefits you're entitled to, SuperFi aims to help residents reduce their debts, no matter how big or small they may be

- Ageing & Autism - Manchester Study Findings

See attached slides summarising the findings from the study to review in your own time



SuperFi X Newham London

### Your debts and bills in one app

SuperFi can help to manage debts, boost incomes and reduce expenses - to make paying bills easier


9:41

Outstanding debt  
**£3,931**

B	Barclaycard £125 due 15/09/22	-£3,056.00
N	Natwest £125 due 27/09/22	-£645.00
K	Klarna #1 £70 due 27/09/22	-£140.00

View all accounts

Tackle the cost of living crisis



Sign up now

MAYOR OF LONDON

sky NEWS

"SuperFi helps people view and manage all their finances in one place."

"A consumer debt start-up aimed at helping Britons weather the cost-of-living crisis"

SuperFi is not regulated for, and does not provide, any debt advice or financial advice. Users are encouraged to seek independent professional advice for their specific financial situations.

- Ageing & Autism - Manchester Study Findings

## Findings: Physical Health

- Experiences of interactions between autism and physical ageing  
*'Menopause can be particularly destabilising for autistic women compared with neurotypical women. If I'd known that I maybe would have been able to ride it out better.'*
- Fears of autism as a risk-factor for age-related illness  
*'I think there's an increased possibility of dementia [...] for people that have got autism. And, okay, that's going to be horrible if it happens. But at least if I know there's a possibility it might happen, I can be looking out for the signs [...] not in a negative way, [but] in a practical way. [...] I can start doing the things that might help'*
- Autism can make it more difficult to engage in preventative health behaviours  
*'Inertia can be a theme for autistic people.'*



- Ageing & Autism - Manchester Study Findings

## Findings : Age-Related Changes

- Some aspects of autism became more challenging with age

*'I think the [sensory] triggers get worse. What I wouldn't necessarily notice so much as a young person, I'm now immediately screaming in my head.'*

- Changes in ability to 'mask' autistic characteristics

*'You know, we still have the same problems and issues we might be better controlling them or managing them or masking them.'*

*'As you get older, the question of just the amount of energy you have to be able to do the masking'*

- Concerns around changes in caring responsibilities

*'My mother's part of my support network [...] And I know it's something that everybody gets to in middle age, to worry about the parents [...] and what they're gonna do about their care. And I think that's magnified to some extent with autism, because I know that I could not go and stay at hers and look after her'.*

- Ageing & Autism - Manchester Study Findings

## Findings : Social Support

- Difficulties in building supportive social networks *'I take care of myself. I generally have difficulty dealing with other people'*
- Increased reliance on family for social support *'A lot of autistic people end up staying at home with their parents'*
- Autism as a risk factor for social isolation in later life *'Older people tend to progressively lose out on social contact. And if you if you've had a fairly low level of social contact to start with, which autistic people probably do, then it may be more important to retain what little I do have.'*



- Ageing & Autism - Manchester Study Findings

## Findings: Knowledge and Attitudes

- A need for more knowledge about ageing with autism *'Autistic people do need to know what's going to happen as they get older.'*
- A lack of older autistic 'role models'. *'There are not very many over 50s who even have diagnoses and very few over 70. So how are we even supposed to know what happens when we get older?'*
- Need for greater knowledge and understanding of autism within services *'We can, well, be seen as difficult clients, which might reduce the quality of the support we get.'*

- Ageing & Autism - Manchester Study Findings

## Findings: Seeking Formal Support

- Barriers to accessing support

*'Executive functioning and my ability to engage with the world really fluctuates so that when I'm overwhelmed, I lose a bit of speech.'*

- Many health and social care services are not suitable for autistic people

*'[My GP] have the radio and it's just a massive trigger. And then there are kids they're running around and screeching and banging on the toys. [...] We cannot seek the health care that we need because seeking it is worse than any illness.'*

*'One of my worst nightmares is ending up in an old people's home because I have these sensory processing difficulties. So being in an overheated room that's far too warm with a lot of other people with a TV up turned over full blast [...] is literally one of my worst nightmares.'*

- Ageing & Autism - Manchester Study Findings

## The SPACE Framework e.g. Doherty et al (2023)

- Sensory Needs
- Predictability
- Acceptance
- Communication
- Empathy



Autistic Spaces are events/places where autistic needs have been considered.

Doherty, M., McCowan, S., & Shaw, S.C.K. (2023). Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings. *British Journal of Hospital Medicine*, 84, 1-7. <https://doi.org/10.12968/hmed.2023.0006>

# Dates of next meeting

Monday, 8th July 2024	9.30am registration 10:00 - 11.30am	<b>Stratford Library</b> Hopkins Room Online and in-person
Tuesday, 8th October 2024	9.30am registration 10:00 - 11.30am	<b>Canning Town Library</b> Elizabeth Fry room Online and in-person
Monday, 27th January 2025	9.30am registration 10:00 - 11.30am	<b>Stratford Library</b> Hopkins Room Online and in-person

**THANK YOU**

Have a Nice Day!

