

# AAC Users' Group

**Contributors:** Fazil Baksh, Andrew Stuart, Bruce Stuart, Shay

**Facilitators:** Ridwana Akhtar (Speech and Language Therapist) and Flavia Remartino (Speech and Language Therapy Technician), Assistive Communication Service (ACS)



- Who we are
- Our story
- Positive outcomes
- What has changed in our practice
- AAC users' testimonies
- Questions

# The group began with lots of ideas...

A white thought bubble with a blue outline, containing the text 'AAC user-led'.

AAC  
user-led

A white thought bubble with a blue outline, containing the text 'Peer mentoring space'.

Peer  
mentoring  
space

A white thought bubble with a blue outline, containing the text 'Developing leadership skills'.

Developing  
leadership  
skills

A white thought bubble with a blue outline, containing the text 'Structured sessions'.

Structured  
sessions

A white thought bubble with a blue outline, containing the text 'Space to create new opportunities'.

Space to  
create new  
opportunities

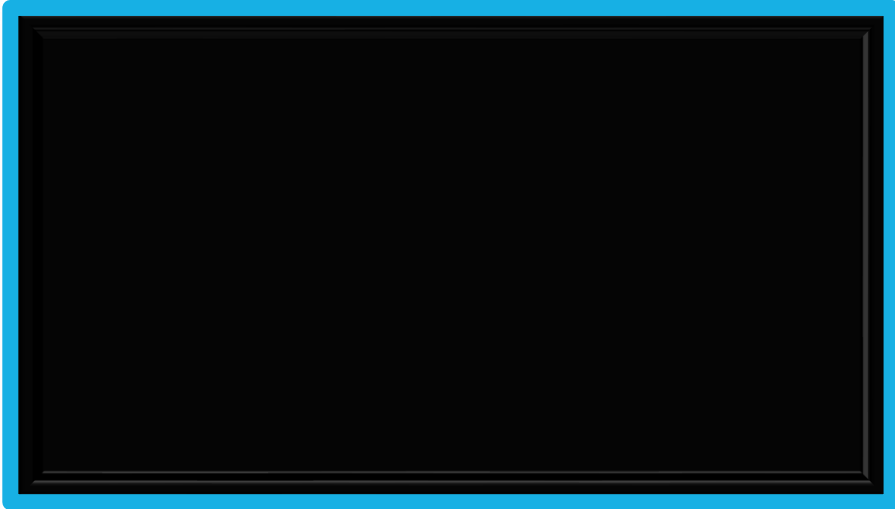
## The group is...

- ✓ Monthly AAC group
- ✓ Free
- ✓ Located in Central London
- ✓ Accessible
- ✓ A safe space to talk about interests and lived experiences

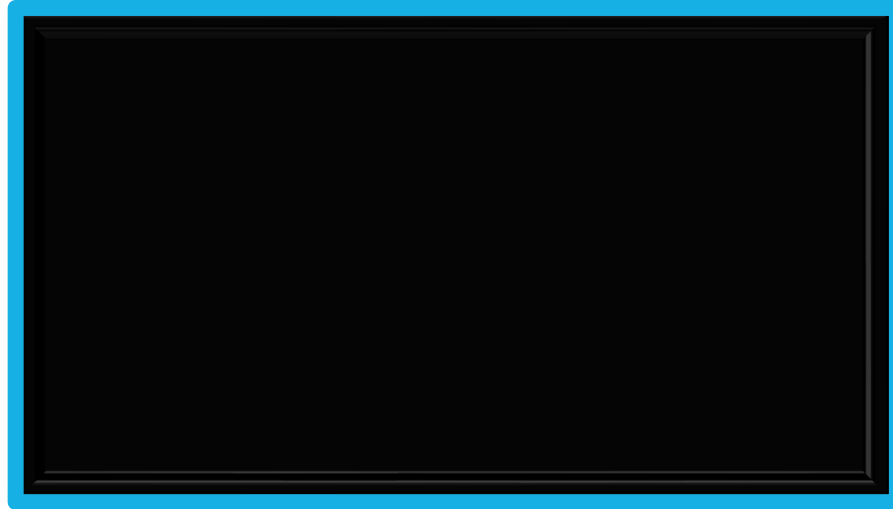
## The group is not...

- ✗ A therapy session
- ✗ A lecture
- ✗ A meeting with an agenda

# Andrew's conversation with Judy

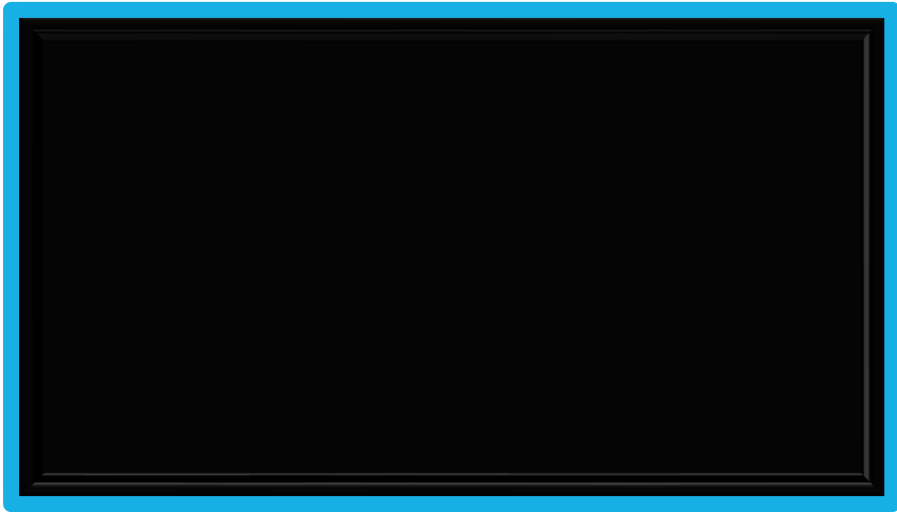


Where did you go?

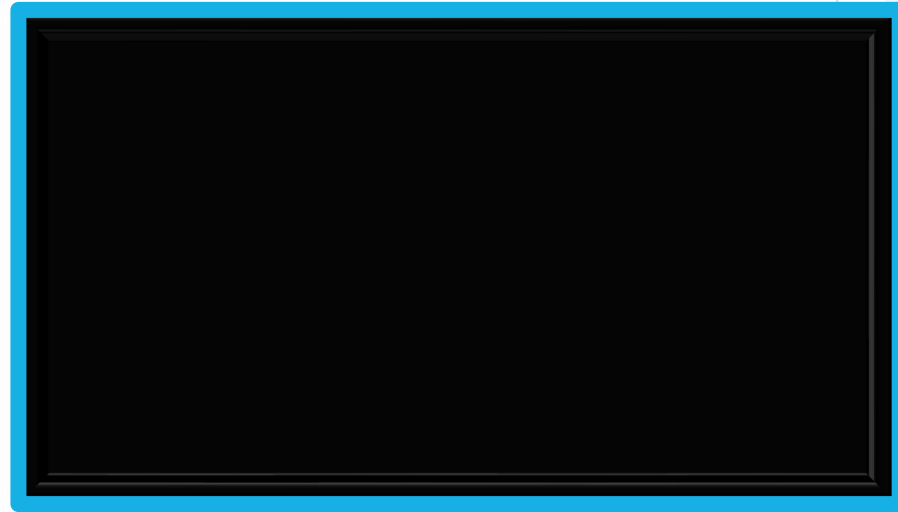


Who did you see?

# Andrew's conversation with Judy



How often do you go to group?



Do you have any ideas for the group?

## What happens naturally

- ▶ Experienced AAC Users supporting newer users
- ▶ Sharing hacks & travel shortcuts
- ▶ Honest stories about real life with AAC (and without)
- ▶ Organic mentoring. No forcing it.

## Why 'naturally' matters

- ▶ No pressure or expectations
- ▶ A space to just...communicate.

Because carers/family told us:

'There's nowhere informal to just talk' and 'Everything feels clinical.'

## *The facilitators' role includes...*

- Sending monthly reminders (emails, sometimes calls)
- Booking the room and other accessible needs (e.g. hoist)
- Bring tea and biscuits (**important!**)
- Take informal notes, to share helpful resources or fun recommendations (e.g. films, parks, cafes).

# Positive Outcomes

## ***For The Service***

- Opened beyond our caseload
- Understanding and supporting families/carers
- Networking opportunities
- Volunteering opportunities within the Trust (work in progress)
- Conference participation
- Support best practice

*'The AAC communication meetings are beneficial for everybody. I am quite blessed to have met some truly wonderful people. I want to thank the team of speech specialists to provide this opportunity and I hope the group continues.'*

*- Shay, Fazil's sister*

# How has our practice developed?

## ***We've become better advocates***

This group doesn't fit neatly into:

- Targets
- Outcomes
- KPIs

But it matters.  
So we protect it.

## ***We are comfortable with:***

Slowing down  
Allowing silence  
Respect pace  
Prioritising access over efficiency

## ***Accessibility hits differently now***

We've seen what it takes to attend:

- Travel planning
- Weather
- Carer availability
- Energy levels/health

So we run it every month.  
Consistency = respect

## ***We better understand carers***

The emotional load  
The advocacy battles  
The system navigation  
We are mindful of above during our interactions.

# Positive Outcomes

## ***For Carers***

“We need our own space too.’

‘It is important to connect with people who share the similar journeys and through the group I have enjoyed the connections with other families. We are now initiating a "family carers support" network where we would meet outside for lunch.’

‘As a sister who cares for Fazil full time now, I have watched Fazil’s growth. These meetings offer a safe space to dialogue. Watching Fazil have this space to look forward to definitely helps me to feel better about his growth. ’

# *Positive Outcomes*

## *For Users*

- Making meaningful connections
- Opportunity to use AAC
- Confidence using AAC device outside of 'sessions'
- Sharing lived experience
- Exploring London /having a day out

# Fazil's experience

Going to a café with eye gaze device



How was it?



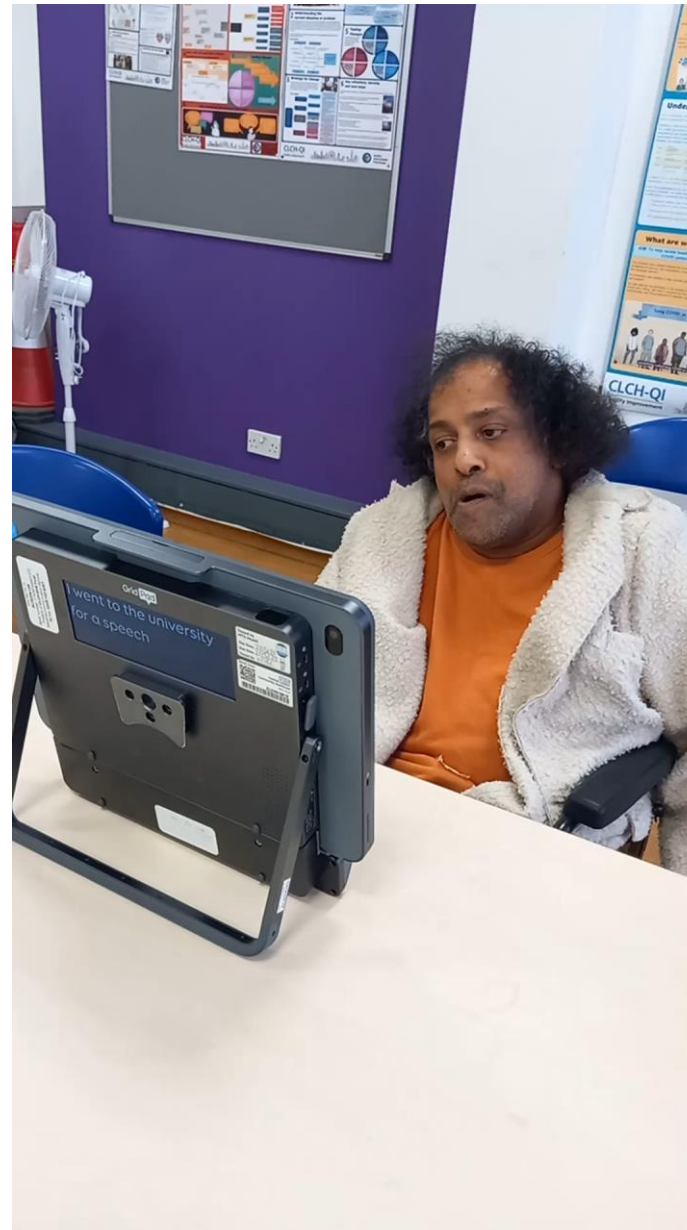
# Fazil's experience

Over to Fazil!



# Fazil's experience

What other opportunities have you had to use AAC / raise awareness about AAC?

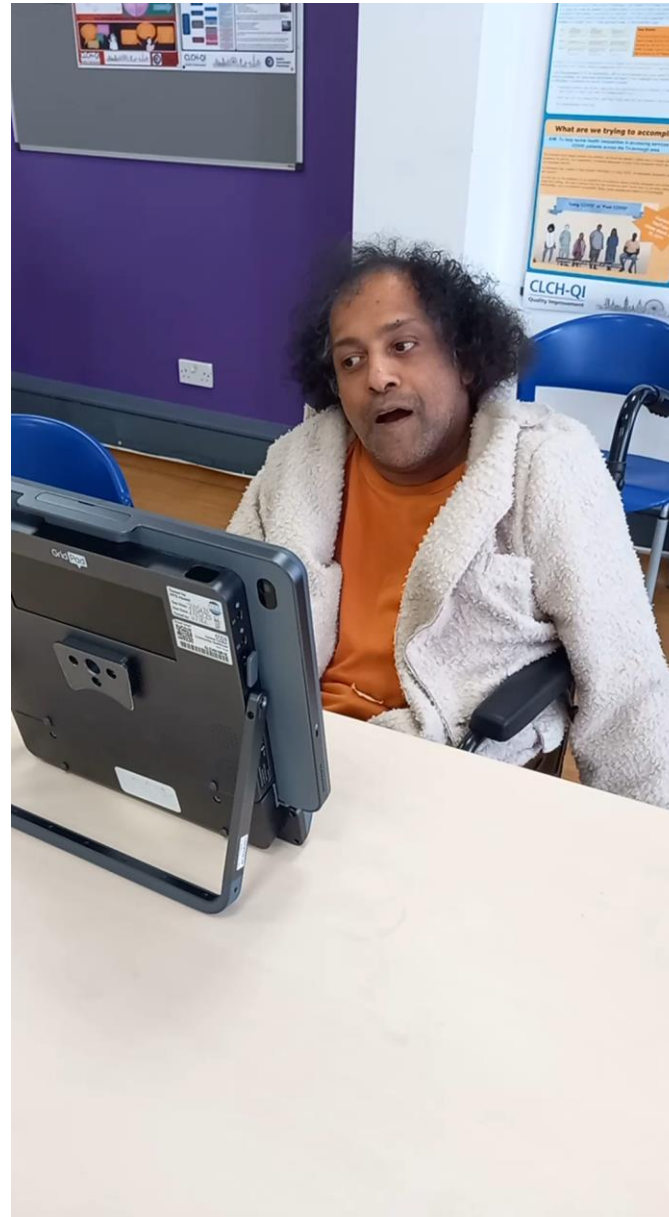


# Fazil's experience

What exciting things have you done with your AAC recently?

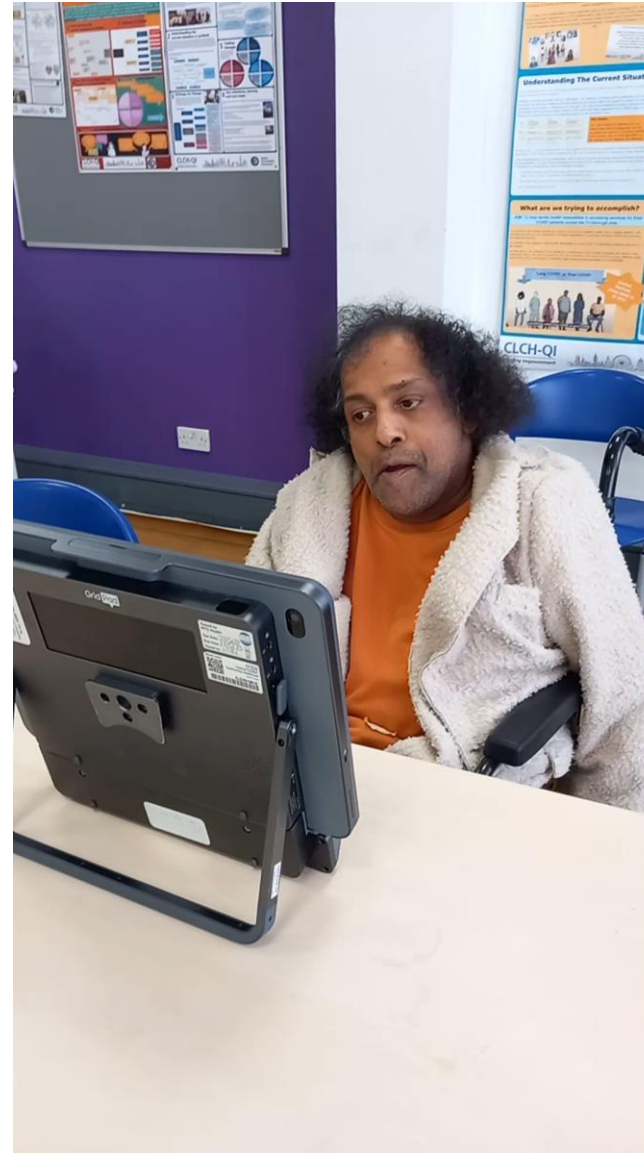
Where have you communicated with people?

(A: restaurants and mosque)



# Fazil's experience

Fazil shares how other people react to his eye gaze device



# The journey so far...

## **The reality is better!**

- Flexible sessions, with no agenda
- Growth in self-confidence with using AAC
- Making friends
- Learning from sharing personal experiences and tips as AAC users and carers/family
- Exploring volunteering opportunities
- Exploring development of a carers network
- Attending CM event!

Thank you and  
now over to  
you:  
any questions?

