



# ALAG Newsletter December 2019

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## Comments from the Chair

On behalf of the ALAG Trustees I would like to welcome all members to the new ALAG newsletter. It is the intention of this newsletter to enable the members to read about all the different events and general news in ALAG, past and present. Also there will be an opportunity for members to contribute by writing articles about themselves and ALAG in general. I wish all those who will be working on this newsletter the very best of luck in the future. Added to this I shall take the opportunity to say that I shall be stepping down as Chair at the end of the year and John Harrison will be taking over as interim Chair as from January 2020.

*Desmond Meldrum Chair ALAG*

## ALAG Support Service update

2019 has been a big year for ALAG. We celebrated our 5th anniversary as an independent charity with our popular Conference 'Overcoming Barriers: Neurodiversity in Autism'. We were also invited to have our first exhibition stand at the Autism Show in June. You can read about both events in this newsletter. We are delighted with the work we've done so far and we now have a desk space and access to meeting rooms every Wednesday at the Voluntary Action Islington offices. We continue our much needed work supporting our members with matters ranging from employment issues to accessing suitable housing. As ever, we are grateful to those who have encouraged and supported us along the way and to all of you, our members, for the part you play in helping ALAG to grow and develop as a highly valued and established group by attending and participating in our meetings.

*Ethney Anderson ALAG Facilitator*

## ALAG meetings review

We had a great year of meetings with lots of stimulating talks and discussions. Here is a short summary of each of the sessions:

**8/1/19 - Specialist Social Issues** - James Sharpe, autism social worker in Hackney. James gave a presentation on the Care Act Assessment as it relates to autism.

**5/2/19 - Giving too much away** – John Harrison led out on a group discussion on how autistic people can sometimes give away too much information and how it can lead to problems.

**5/3/19 - Autism & Mental Health** - Ricki did a wonderful presentation on why autistic people have such a high incidence of mental health problems and some of the issues they present with. She also offered strategies that might help to deal with concerns, such as anxiety and identifying emotional states.

**2/4/19 - WAAW Quiz – Nick Stone** expertly and entertainingly facilitated an informative quiz for World Autism Awareness Week.

**7/5/19 - Specialist Social Issues part 2** - James Sharpe continued the discussion on how to get support from Adult Social Services for autism-related needs.

**5/6/19 - Bullying** – Ethney Anderson facilitated this group discussion where ALAG members shared their experiences of being bullied at school, at home and in the work place. It showed just how widespread this problem is among our members and among autistic people more widely.

**2/7/19 - Autism & Ageing** - Alice Harwood from the Tavistock shared her interesting research findings on Autism & Ageing.

**6/8/19 - Summer Social & the BIG Quiz** with Nick Stone. Another exciting time was had by all!



ALAG Summer Social buffet at Islington Town Hall

**3/9/19 - Adaptations to CBT for Autism** - Richard Pender, Clinical Psychologist and researcher at UCL is looking at how CBT can be adapted to better support autistic people with mental health needs.

**1/10/19 - Moving from Disability Living Allowance (DLA) to Personal Independence Payments (PIP)** - Alex Wood and Paddy Cullen from the Income Maximisation Team explained the application process for PIP, the differences to DLA and answered general questions on the topic including why some applications are unsuccessful.

**5/11/19 - Autism & Romantic Relationships** – This session was a mix between a presentation and a discussion on the topic. The session raised a range of points that were keenly discussed by our members.

**3/12/19** – December ALAG meeting was cancelled due to shortage of rooms at the Town Hall around election time. However, planning continued for our end of year Christmas Meal at the Alwyne Castle.



*ALAG members at the 2018 Christmas Meal*

#### **Dates and venue for ALAG meetings in 2020**

7 January	Town Hall Committee Rm 1
4 February	Town Hall Committee Rm 1
<b>3 March</b>	<b>Town Hall Rooms 5&amp;6</b>
7 April	Town Hall Committee Rm 1
<b>5 May</b>	<b>No Room - elections</b>
2 June	Town Hall Committee Rm 1
7 July	Town Hall Committee Rm 1

4 August	Town Hall Committee Rm 1
1 September	Town Hall Committee Rm 1
6 October	Town Hall Committee Rm 1
3 November	Venue TBC
1 December	Venue TBC

Our thanks goes to Ellie Chesterman for arranging the Town Hall venue for our meetings.

#### **ALAG at the Autism Show**

The Autism Show is already almost a distant memory! It took place in the middle of June over two days at the London Excel. ALAG/the Autism Hub was offered a stall for both days and we were, thus, able to promote the good work our organisations are doing at the fair.



*A talk at the Autism Show*

We sold some of our ALAG bags and Autism Hub badges and gave out lots of leaflets about both organisations. We also began to invite people to the conference we were starting to plan for (and that was indeed held in) October. This being the Autism Show, most stalls were aimed at children and teenagers which was, although predictable, a bit disappointing. However, our stall was proud to do something towards redressing the balance and people showed much interest in our work with adults on the spectrum and we had many enquiries.



Alain English - explaining his involvement with ALAG to someone visiting the ALAG stand at the Autism Show.

### ALAG Sponsored walk

Our annual Sponsored Walk fundraising event took place this year on Sunday 22 September in central London. We were delighted to receive a generous food donation from Tesco's Caledonian Road store in support of our sponsored event. Our thanks go to the Caledonian Road store manager Daniel Treske and his colleague Abdul for supporting our event and providing our walkers with refreshments throughout the day for the third year running.



Ethney Anderson and Tesco staff with food donation for our sponsored walk.

The walk was planned to be 3 miles long and take place in Regent's Park. We were going to enjoy the park with its autumnal feel while raising money for ALAG to be able to continue its good work. At the time, there were still some roses and other flowers out and the wildlife is always very attractive. The many Canadian geese, coots, moorhens, gulls, ducks, pigeons and the occasional grey heron are sure to be highlights of any visit. Unfortunately for us, however, it was pouring with rain to such a degree that we were unable to go to Regent's Park. This was a great disappointment. While waiting out the worst of the rain, we decided to go to the National Gallery for a while instead, where we looked at many interesting pictures. When we were finished at the Gallery, the weather had cleared slightly and we were able to do our walk via the Mall to Buckingham Palace and St James Park. Altogether, we hope to have ultimately achieved our mileage and to have deserved the money we raised. In the end, we did have a fun day out albeit a very different one from what was planned and we raised over £300 for the ALAG Conference.

*RR – ALAG Volunteer*

### Autism Hub Islington

The Autism Hub Islington came into being in January 2018. The idea for the Hub came about when the Islington Autism Project and ALAG got together to collaborate on how to improve the quality of life for autistic adults by connecting people to resources, services and organisations from a central point, "The Hub". Expert advice, information, support and signposting as well as autism training is available for Islington and Camden service users, their families and carers and other professionals every Monday (except for Bank Holidays).

Originally, the Hub was located at the Courtyard School in Islington, where it had its official launch during World Autism Awareness Week in March 2018. The school is a lovely, welcoming place and we are grateful to the head teacher **Deborah Shepherd** to have hosted us.



Elleny Page, a founder member of the Autism Hub, at a Hub workshop in April 2019



Ethney Anderson and Zainab Rahemtulla, founder members of the Autism Hub volunteer team.

Over the last two years, the Hub has gone from strength to strength. In July 2018 we moved to the Time for... Café at 116 Pentonville Road (the old Jessica Kingsley Publishers building), which

has enabled us to open every Monday throughout the year. Also, we now have a shopfront on a busy road with people popping in off the street who see the Autism Hub sign in the window, which is great! We owe a debt of gratitude to the late Roger Kitsis and Ella Celeste for providing us with the ideal premises for our work.

In October 2018 we had an autism awareness event at the Time for...Café, to launch the services available at the Hub. Professionals from a range of services attended, including Emma Whitby from Healthwatch Islington, local Police Officers, a representative from Arsenal Foundation and someone from Camden and Islington mental health services. The services we have been offering at the Hub include a drop-in service and a counselling service and where we also deal with a range of other needs, ranging from peer support to help with housing, benefits and employment. In addition, we are offering workshops.

We have run a pre-diagnosis support and a post-diagnosis support workshop, a money sense workshop and a creative expression event where members of the Hub and ALAG and friends performed comedy acts and poetry. This event was facilitated by Mark Burkwood, an autistic comedian. We have recently started a stand-up comedy course as a confidence building activity running for six weeks, also facilitated by Mark.

The *IslingtonTribune* newspaper published an article about the work of the Hub (see below)

***'Charity to the rescue of autistic adults who miss out on support'***

*Autism Hub holds weekly drop-in sessions at café, but plans full-time operation*



Autism Hub Volunteers: Heather, Nick, Marilla, Dermot and Zainab

*A GRASSROOTS charity which provides much-needed help for autistic adults aims to raise thousands of pounds to expand.*

*The Autism Hub has recently opened a one-day-a-week drop-in session at a Pentonville Road café but wants to become a full-time operation.*

*It was founded last year when Ethney Anderson, Zainab Rahemtulla and Ellen Page, who were working in autism support, realised there was little provision for adults diagnosed with autism later in life. Some adults fall through the gap, they say, if they have been diagnosed with high-functioning autism or Asperger's and do not meet the eligibility for health and social care services.....' 17 August, 2018 — By Samantha Booth (The full article can be found on the ALAG website)*

Finally, the Hub volunteers have been commended as runners up for **Volunteer Team of the Year 2019 by Voluntary Action Islington.**



Ricki with furry friend Tom and Tom's owner Ella  
**Service Users testimonials**

*"Following a late diagnosis of Asperger's Syndrome, I found out about The Autism Hub. I had been experiencing major difficulties with my housing for many years, which had resulted in ongoing stress and acute anxiety. Ethney supported me, and a few months on my daughter and I are now living in much more suitable accommodation. This has completely improved our quality of life and hope for the future. I am very grateful for the support and kindness received."* C.B.

*"I have never felt so at home and accepted like I feel at the Autism Hub. I found incredible support every time I needed it. Now, it doesn't matter how anxious I become; I know I can depend on the Hub to support me."* M.B.

## ALAG Conference 2019 report

On Thursday 17 October 2019, ALAG held its first conference to celebrate five years as an independent charity. The conference entitled **'Overcoming Barriers: Neurodiversity in Autism'** was held at the Indian YMCA near Warren Street. Over 70 people attended and the event was extremely well received. The goal of the conference was to improve delegates' understanding of what it feels like to be autistic, how autistic people may present, some issues/barriers that may arise in their lives and how to move towards overcoming them. To this end, ALAG brought together as speakers both autistic people and professionals working in clinical or research settings to share their insights on different facets of the condition and life with it. We also had a contribution by a mother and an uncle of an autistic teenager, who spoke movingly about their care and support for him.

The morning started with a very informative talk on **autism and gender identity** by **Ruth Millman**, in which she shed light on transgender identities. The topic is important as autistic people are much more likely than neurotypical people to be transgender or to not identify with traditional gender roles. Ruth also gave thought to the difficulties of being doubly marginalised in society: once by virtue of being autistic and once by being transgender. She is planning to set up a trans group for autistic people in the new year.



Ruth Millman, Alongside Autism

The next presentation looked at **autism and mental health support**. Based on lived experience, it focused on ways people can make mental health support more accessible

to autistic people. Topics considered included, among other things, communication, adjustments to therapeutic interventions and practical tips to deal with emotions.

After a short break for refreshments, **Dr Jason Crabtree** spoke on **autism and ageing**. Based on his recent research, he discussed how the cognitive profiles of autistic people tend to differ from that of neurotypical people and how these differences seem to remain stable over time as they age. Towards the end of the talk, he also discussed **executive functioning** in autism, another fascinating area.

Lunch offered the opportunity for networking over some delicious original Indian food.

The afternoon session began with **Alain English**, an ALAG member, who offered the audience an insight into his **life and experience of autism through poetry**. The performance eloquently brought home some of the very real difficulties autistic people experience on a daily and ongoing basis. This was followed by a fantastic talk on **autism in girls and women** by **Dr Will Mandy** from University College London, which explained how and why autism can look different in girls and women and might get missed by diagnosticians. He discussed both differences in presentations and trajectories but made it clear that these are tendencies as some boys/men present more like girls/women and vice versa.

**Jennifer Barker**, ALAG member, related her **own experience of autism**. Two things stood out from her talk: first, how difficult it can be to realise one is different from most other people and the impact this can have on self-confidence and second, that, regardless of being autistic, it can be possible to have a meaningful and successful life.

The last speaker, **Wendy Tuson**, a Speech and Language therapist, gave an intriguing **look behind the scenes of the social communication group** she facilitates for the NHS. She explained how she learned what works and what doesn't and why. It was refreshing to see with how much thought and care she and her co-facilitator invest their work.

The conference was brought to a flamboyant close by Alain who had listened carefully the whole day and created and performed a **poetry medley** based on the conference themes.

We want to thank our amazing speakers, sponsors and volunteers. A big thank you to all our volunteers who worked so hard to ensure the day was a success. It was great that this conference was a true collaboration between autistic and neurotypical people with the shared goal of improving understanding about and acceptance of autism.

The full version of this report can be found on the ALAG website: [www.alag.org.uk](http://www.alag.org.uk)



The Conference Team including our Speakers: Jason, Jennifer, Will, Alain, Wendy who gave of their time and expertise to ensure the conference was a huge success for ALAG.



Helen Pedder and Gillian Scampton, Architects who sponsored our Conference.

#### Feedback from conference attendees:

*"All talks were fantastic."*

*"Incredibly informative – This will help me to support my autistic colleague more effectively." R.Y.*

*"Great to have such a variety of speakers – balance of research, practical and personal experience." J.G.*

*"Discussions of current research trends, experiences and approaches/adaptations I can draw on in my practice." A.J.*

*"Feel inspired to read more and will look up references." J.A.*

*"Lovely to learn about issues in autism-friendly space." A.H.*

*"Excellent. I learned a great deal about autism." G.U.*

#### Ernest Ricketts

It was with great sadness that we learned of the death of our dear ALAG member, Ernest Ricketts.

Ernest was a unique and irreplaceable character, a young man who was passionate about equality and the rights of disabled people. He readily shared his views on many topics and always offered a friendly handshake at the end of each meeting. Ernest will be sadly missed but will always be remembered with great fondness. RIP



Ernest receiving his Work Skills Certificate of Achievement from Frank Dobson MP

**ALAG is grateful for the kind support of our funders**



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