

Hampshire Autism Partnership Board

Tuesday 17th September- 10.00 - 12.30 (via Teams)
Chairing meeting today – Margaret White

Present:


Margaret White - Co-chair of HAPB, Hampshire Autism Voice member
Jason Norum - Head of Commissioning young adults, Learning Disability, Mental Health and Physical Disability, HCC – Adults Autism Lead
Zoë Beasley – Hampshire Autism Partnership coordinator (& Minute taker)
Michael White – General Practitioner, Hampshire Autism Voice member
Roy Banda (on behalf of James Breeze) - Dynamic Support Practitioner, Frimley CCG
Andrew Lund - Area Director Northwest & Autism Lead for Children’s and Families, CSD, HCC
David Carter - Hampshire Autism Voice member, Chair of NAS South Hampshire
Rachel Carter - Hampshire Autism Voice member & Vice chair NAS South Hampshire
Tina Woodcock - Lead for Keyworker programme, HIOW ICB
Alice Madden-Curtis - Deputy Autism Adult Lead & Commissioning Officer AHC, HCC
Paul Richardson - Chair of Hampshire Parent Carer Network
Vanessa Cosby - Hampshire Autism Voice coordinator & Autism Ambassador admin
Gemma Langman - GP and Clinical Champion for Learning Disabilities and Autism
Robyn Kohler - CEO Citizen’s Advice Hampshire
Leigh Drury - Early Years inclusion team leader, CSD, HCC
Sgt Emma Pragnell - Out of court disposals, Hampshire Constabulary
Chris Williams - Head of Service North & NE Older Adults, HCC
Katie Board - IAG and Serendipity lead, Autism Hampshire
Julian Radcliffe - County Education Manager & Head of Ed Psychology, HCC
Alienor Chartier – Equality, Diversity & Inclusion Officer, Hampshire FA
Denise Long - Hampshire Autism Voice member

Apologies:

Cllr Lesley Meenaghan - Co-chair of HAPB & Hampshire County councillor
Catherine Barnard - Transformation Lead, Hampshire All Age Autism and ADHD, HIOW ICB
Adrian Clyne - Learning and Development Officer, HCC
James Breeze - LD & Autism Transformation Manager, Frimley ICB
Maria Hayward - Learning and Development service manager, AHC
Alyson Miller - Hampshire Autism Voice member
Sue Cochrane, Public Health Consultant, HCC
Karina Hourd - Group Director of Business Development, Avenues Group
Ashleigh Spice - Specialist Mentoring Service Lead, Autism Hampshire
Alison Dyer - Disability Employment Advisor Lead for Solent and IOW, DWP
Tim Davis - Associate Director: Children’s MH Transformation / Maternity & Child, ICB

Agenda:

1. [Minutes of last meeting \(March 26th\) Action Log & and matters arising](#)
2. [Hampshire Autism Voice Briefing Paper](#)
3. [HCC updates](#)
4. [Health updates](#)
5. [Tor final sign off](#)
6. [Strategy updates](#)
7. [Prevent strategic plan update](#)
8. [HAPB website](#)
9. [Any other business](#)

Item	Subject	Action
1.	<p><u>Minutes of last meeting (March 26th) Action Log & and matters arising</u></p> <ul style="list-style-type: none"> • Introductions given by all, and apologies listed. • No concerns or corrections arising from previous minutes <p>Action log:</p> <ul style="list-style-type: none"> • Action outstanding from March 2023 for Lynne Tapp regarding disordered eating. Tina Woodcock provided an update that a disordered eating and health inequalities project is commissioning a service which Koala academy will run with online courses for general practitioners. There is one-off funding available for disordered eating and Avoidant/restrictive Food Intake Disorder (ARFID). Pending approval at time of meeting. • Action outstanding for Jason Norum to link Gemma Langman with public health for ongoing projects, Jason aware and will follow up. 	<p>1. send project spec to ZB to share to HAPB core – TW</p> <p>2. Bring Koala into board re project - ZB</p>
2.	<p><u>Hampshire Autism Voice Briefing Paper (David Carter)</u></p>  <p>HAV Briefing paper for the HAPB Sept 202</p> <p>David highlighted key points from the Hampshire Autism Voice report (as attached), overview of items discussed:</p> <p>Autism Ambassadors:</p> <ul style="list-style-type: none"> ○ 31 new ambassadors appointed, bringing the total to 1,171. ○ Annual Conference: Scheduled for 14 November 2024, with nearly 60 bookings already. There will be two autistic speakers, and a unique sensory workshop is planned. ○ 152 ambassadors renewed currently, bringing in about £1,000. <p>Hampshire Autism Voice Membership:</p> <ul style="list-style-type: none"> ○ Role descriptions and terms of reference updated. Efforts to recruit new members being made, particularly an autistic male. <p>Other Involvements:</p> <ul style="list-style-type: none"> ○ Participation in the Hampshire Carers Partnership, LD Working Group, and Personal Expert Panel Partnership. Provided examples of co-production within the board. <p>Health Inequalities and Core 20+5:</p> <ul style="list-style-type: none"> ○ This initiative aims to focus on the 20% most deprived population, identified through various indices such as geographical areas and income levels. The “5” refers to five local priorities, which include learning disabilities and autism. It is an area that will reach many autistic individuals but concerns noted that focus is still often toward Learning Disabilities. ○ Hampshire has been selected as one of four test sites for the CQC’s (Care Quality Commission) Integrated Care Systems Engagement and Inequality Improvement Network. This network aims to improve engagement and address inequalities within integrated care systems. <p>Michael White highlighted several key points:</p>	<p>3. look to link with ICB health and care inequalities board. GL/ZB</p> <p>4. bring LeDer as input – ZB</p>

- Health inequalities are a significant focus area due to the ICBs statutory requirements as required by the Health and Care Act 2022.
- Data Challenges: There are challenges in producing and analysing data specific to autism; autism data is more complex to gather and analyse.
- Death Certification Process: Highlighted the recent changes in the death certification process, where every death must now be reviewed by an external medical examiner. This change may improve the reporting to LeDer of deaths in individuals with diagnoses of learning disabilities and autism during the process of death certification.

Gemma Langman discussed LeDer ([Learning from Lives and Deaths](#)) and the need for better reporting of deaths in the autistic population. Key points included:

- Underreporting of Autism: deaths solely due to autism are often underreported. In the two years she has been attending panel reviews, only one death with a sole diagnosis of autism was reported.
- Focus Reviews: Not all reported deaths go to a focus review as focus reviews are conducted for specific reasons, such as concerns or notable care outcomes.

Tina Woodcock provided additional insights on the ongoing work with population health analytics to address health inequalities. Key points included:

- Population Health Analytics: Mentioned collaboration with Katie Taylor on population health analytics, focusing on health inequalities for learning disabilities and autism.
- Data Extraction: Shared that the ICB is now looking to pull in robust data to identify health inequalities within the cohort of individuals with learning disabilities and autism.

Questions/Comments:

> Jason Norum: Raised a question about the visibility of results from the LeDer reviews. He emphasised the need for feedback on what went right or wrong in local systems to improve services.

Gemma responded that she chairs the reviews and agreed that it needs improvement – key has always been to feed results back to partners or providers. There have been recent improvements in the review process, with a smaller panel involved and the outcomes being fed back directly to relevant boards to implement changes.

> Michael White: Suggested that the board should consider bringing in more detailed discussions on health inequalities and the LeDeR reviews during a future meeting. He emphasised the importance of understanding and addressing health inequalities for autistic individuals and other neurodiverse conditions.

Zoë will look to bring more detailed input on health inequalities and LeDer reviews to future meetings.

3. HCC updates (Jason Norum)

Jason detailed a few Hampshire County Council (HCC) senior management personnel updates (via chat):

- Jess Hutchinson now confirmed as Director of Adult Services.
- Jason Brandon in temporary role as Assistant Director for Younger Adults (18-65) and Principal Social Worker.
- Gail Kirby in temporary role as Assistant Director for Older Adult Commissioning and HQ services.

Autism Information and Guidance (IAG) Service

- Public Health will fund the IAG Service beyond March 2025. This decision ensures the continuation of a crucial service that supports autistic individuals their families in the longer term.
- Alice Madden-Curtis will continue to work on the service specification, with a focus on co-production to involve stakeholders in the design and delivery of the service.
- Public health will also have input into the service specification to ensure the service aligns with broader Public Health goals.

Enhanced Support Work Service

The service has been in place for the last three years with two providers working with the Multi Agency Safeguarding Hub (MASH) to provide an on-the-ground response for self-neglect cases.

- It has been funded through latent COVID funds, which have been stretched to cover the service until March 2025.
- There is no need for Care Act eligibility
- Service has seen a high prevalence of autistic individuals or those suspected to be undiagnosed autistic individuals being supported.
- This service has been able to engage positively in a way that MASH teams have been unable to engage

The service has received positive feedback for its impact on individuals in poor social circumstances. There were concerns about the future of the project with funding ceasing, but it has been confirmed that the two providers are going to maintain the outreach offer as part of their BAU. The long-term outlook now looks positive.


Expenses Policy Review

Zoë discussed there is currently a review of the expenses policy documents. The review aims to clarify engagement level profiles and simplify the policy documents.

Key discussion points from the policy meeting included:

- Document language: The current policy documents are very wordy and corporate. The review aims to create plain English versions to make them more accessible.
- Preparation time for meetings: There is a need to establish clear guidelines on how preparation time for meetings is compensated.

	<ul style="list-style-type: none"> • Legal considerations: Zoë has sought additional clarity on legal aspects to ensure the policy does not inadvertently discriminate against individuals who may need more time for preparation. <p>Zoë invited Margaret and others to contribute to the review process to ensure it meets the needs of all members.</p>	
4.	<p><u>Terms of Reference (ToR) final sign off</u></p> <p>Zoë discussed the updated ToR for the board. The review aims to ensure the ToR reflects current practices and includes necessary provisions. Key points included:</p> <ul style="list-style-type: none"> • Recording Meetings: Need to include a statement in the ToR about recording meetings so that it is formally documented. • Bribery Act: There was a query about whether the Bribery Act should be referenced in the ToR or in the expenses policy. This is particularly relevant for those engaging at Level 3 co-production, where members may have access to sensitive information. The aim is to ensure members understand the confidentiality and ethical considerations involved. <p>Zoë suggested further discussion with key members to discuss these topic areas before finalising the terms.</p>	5.arrange meeting with key members re ToR - ZB
5.	<p><u>Health updates</u></p> <p>Zoë explained that significant changes and restructuring are happening within the health sector currently; outcome of decisions area expected in the next week or so. Due to the timing, it was not appropriate to present the full information yet, so this will be postponed until December's board.</p> <p>Zoë, on behalf of Catherine Barnard, provided a brief overview of the ongoing changes and restructuring within the health sector, particularly focusing on the neurodivergence pathway.</p> <p>Key points included:</p> <ul style="list-style-type: none"> • Draft Image of Neurodiversity Pathway: draft image shared of the proposed neurodiversity pathway, which is still in development. This image, created by Anthony Harper, aims to provide a comprehensive view of how neurodivergent individuals with may navigate the health system. • The image is not finalised so cannot be shared publicly at this stage. • The proposed pathway emphasises a holistic approach to supporting neurodivergent individuals. It draws parallels to how physical health issues, such as arthritis, are managed to look at a phased process of need approach. • Children's and Adults' Pathways: The pathway includes separate considerations for children and adults. For children, it emphasises parental support, educational support, and profiling tools to assess sensory and communication needs. For adults, the pathway is still being designed, and there is no consistent plan in place yet. • The co-design phase will involve stakeholders to ensure the pathway meets the needs of neurodivergent individuals. 	

	<ul style="list-style-type: none"> • Data and Mapping: The pathway development involves mapping existing services and identifying gaps. This work, led by Tina Woodcock and Gemma Langman, aims to ensure that support services are available across all of Hampshire. • The goal is to transition from a diagnostically led approach to a needs-based approach. • Representation: Catherine Barnard has confirmed going forward there will be specific representatives for Hampshire, Portsmouth, Isle of Wight, and Southampton. This will help ensure consistent representation and engagement with the board. <p>Profiling Tool concerns: Zoë clarified that the potential use of profiling tools discussed in some previous meetings are not intended to gatekeep or reduce access to autism assessments. Instead, they aim to better understand an individual's needs, such as sensory and communication profiles do, to provide appropriate support. The terminology used in these tools may need to be adjusted for clarity.</p>	
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<p>6.</p>	<p><u>Strategy updates</u> Zoë provided an overview of the strategy, its aims, six focus areas, 103 recommendations and areas for improvement that were created from the strategy findings.</p> <p>It was emphasised that partners need to complete action plan reports to help the HAPB monitor progress and identify any challenges. The discussion also focused on refining the process and strategy for gathering information from partners, particularly partners such as charities and the Voluntary, Community and Social Enterprise (VCSE) sectors, which influence multiple priority areas.</p> <p>Additionally, we need to consider how to obtain evidence of change from organisations outside the Hampshire Autism Partnership Board.</p> <p>Strategy areas:</p> <ul style="list-style-type: none"> • Training and Acceptance in Society <p>Update sent via email from Maria Hayward:</p> <div style="text-align: center;">  <p>Oliver McGowan bulletin Aug 24.pdf</p> </div> <p>Additional to the attached information from the Oliver McGowan IBC, from an HCC perspective for staff who require training as mandatory for their role we are currently:</p> <p>OM eLearning – mandatory for Tier 1 and 2 training = 94% OM Tier 1 Webinar = 70% Tier 2 sessions to start in the next two months</p> <p>Zoë highlighted various ongoing community engagement initiatives since the strategy's launch, aimed at enhancing understanding and fostering inclusivity. These efforts include an autism awareness</p>	<p><i>6. Discuss future input on the inclusion board's work with focuses on EBE and EBSA – JR/ZB</i></p> <p><i>7. Bring NHSE/prison in for input – ZB</i></p> <p><i>8. Bring NHSE data representative as input - TW</i></p>

session for Hampshire Football Association coaches, assisting in creation of Special Educational Needs (SEN) sessions at leisure centres, trauma-informed provider forums, and more

- **Education Update** from Julian Radcliffe

Julian gave an update about the educational priority of the autism strategy and is reporting to the Children's Transforming Special Educational Needs and Disability (SEND) Board for additional scrutiny.

Key Points:

- Five overarching aims split into pre-16 and post-16 years.
- Employment and training initiatives, for post-16 years involving careers advisers and employers.
- Position statements on Pathological Demand Avoidance (PDA), Applied Behaviour Analysis (ABA), and Picture Exchange Communication System (PECS).
- Collaboration with early years and schools.

Education Engagement and Inclusion

Julian discussed the challenges of education engagement post-COVID, including non-attendance and exclusion rates. He mentioned the introduction of the Inclusion and Education Engagement Board.

Key Points:

- Complex reasons for non-attendance being evaluated (children, family, community & school)
- Hampshire figures are similar to national figures
- Strategic response to education engagement.

- **Employment update**

No current updates from DWP. Zoë is liaising with DWP colleagues to ensure representation for December board.

- **Health Recommendations Updates**

Zoë shared updates on health recommendations, noting progress and completion of certain tasks, particularly in diagnostic services.

Key Points:



- Consistency across diagnostic services.
- Procurement and pathway elements.

- **Inpatient and Community Support**

- Focus on adult healthcare, particularly autism ambassadors being increased in each team.
- Potential to then have training for team to handle more complex need cases.
- Collaboration with public health being explored
- Will be trying to reengage the housing districts via SHOG
- Mental health charter discussions continuing on how we seek to build awareness of this.

- **Criminal Justice Sector (CJS)**

	<p>Sgt Emma Pragnell is the autism lead for the criminal justice side and a new CPS representative has been established which is positive but still struggling to find out who should represent probation which is an area that really needs engagement. Prison service is still engaged, but technology challenges make this complicated.</p> <p>The discussion focused on the integration of health strategies with the prison sector, addressing the needs of neurodivergent individuals in prisons and upon release.</p> <p>Key Points:</p> <ul style="list-style-type: none"> ○ Healthcare provision in HMP Winchester ○ Autistic people are over-represented in prison ○ Data collection on prison population. ○ Challenges in accessing health records in prisons. ○ PREVENT work discussed ○ Easy read documents have been produced centrally around different elements of CJS which is positive step. <p><u>Questions/comments:</u></p> <p>> Michael detailed links between prison populations and autism prevalence and suggested that the health strategy (including LDA strategy) needs to link with some of the criminal justice sector organisations.</p> <p><i>Jason Norum clarified that the healthcare provision within HMP Winchester is provided by Practice Plus Group who are commissioned directly by NHS England. HCC have a section 75 agreement in place with them, which also provides for social care so do have useful links via this contract and regular contract monitoring.</i></p> <p><i>Tina also clarified that when individuals leave prison they will not have been registered with a GP and the contract around managing their healthcare is an outside provider rather than H10W ICB.</i></p>	
7.	<p><u>PREVENT Autism strategic plan update (Zoë Beasley)</u></p> <p>Overview given re the strategic plan. The Prevent and the Autism strategic plan has been developed to address issues of over representation of autistic people in Channel process. It aligns with the wider Hampshire Autism strategy's six focus areas.</p> <p>Zoë emphasised how this crucial topic is approached with sensitivity and understanding, avoiding any stigmatisation of autistic individuals. The focus will be on providing the right support and resources to partners to support any concerns presented to them or dispel myths within communities.</p> <p>Zoë has been asked to lead on implementation of the plan, working closely with the PREVENT communications and education subgroups.</p> <p>Key Points discussed:</p>	

	<ul style="list-style-type: none"> ○ Initial Steps: The first steps involve mapping out information and myth-busting. A small working group will be formed, including individuals like Viv Dawes, an autism ambassador who has worked within the prison services. ○ A survey will be distributed to all PREVENT members to establish a baseline understanding of their training and knowledge around autism and vulnerability. Once we have this we need to ensure any new or updated training is co-produced with autistic individuals to enhance its impact. ○ Future Plans: Zoë is seeking a budget to hold a face-to-face event to discuss these issues in depth and dispel myths. 	
<p>8.</p>	<p><u>HAPB website discussion</u></p> <p>Zoë discussed the updates to the Hampshire Autism Partnership Board (HAPB) website, including the potential for a professional login section to manage sensitive information.</p> <p>Key Points:</p> <ul style="list-style-type: none"> ○ Website Updates: The website is up and running, with final changes being made to link resources and adding a minutes section. ○ GDPR Considerations: previous minutes are held on the Hampshire Autism Voice website. Having discussed with HCC Governance, they concluded that previous minutes should not be included on the new site. ○ Professional Login: There was a discussion about whether a professional login section would be beneficial. This section could house sensitive information and minutes of the ASG, relevant updates, reducing email clutter. One concern is that a private login section might give the impression of a lack of transparency so needs further thought. <p>Zoë requested feedback about the need for a professional login section.</p>	
<p>9.</p>	<p><u>AOB</u></p> <p>Words Matter – Zoë showed a video created by Words Matter about the impact of verbal abuse on children. Words Matter - Words have power</p> <p>PINS – Paul provided an update on the PINS (Programme for Inclusivity for Neurodiversity in Schools) programme. The programme is on a tight deadline, with a completion date of 31 March 2025. Diane Lowth is currently meeting with schools to discuss participation.</p> <p>Research pieces - Research projects - Autism Autistica &</p> <p> New autism research opportunities Sept 20</p> <p>Inclusion - Hampshire Quarterly Information webinar on 17th October – registration details on flyer:</p> <p> Inclusion Hampshire Quarterly Information</p>	

	Next meeting: December 10th	
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Hampshire Autism Voice (HAV) Update Brief to Hampshire Autism Partnership Board (HAPB)

Tuesday 17th September 2024

The following update from HAV covers their activities since June 2024.

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1 Autism Ambassadors

HAV is a partner in this scheme along with Hampshire County Council (HCC), Southampton City Council, Portsmouth City Council, Isle of Wight Council, Autism Hampshire and NAS South Hampshire branch.

- Two training sessions have been delivered since the June HAPB meeting, one online and one face-to-face. A further 31 people have been appointed as Ambassadors, bringing the total to 1271. Another online training session is scheduled in October.
- We welcome back volunteer trainer Angela Thompson, former trainer at Autism Hampshire who is now working for Places Leisure. Angela will co-deliver the October training course.
- The 2024 annual conference will take place on 14 November at Ashburton Hall. Two autistic speakers are already booked, and there will be a sensory workshop delivered by Alison Vasey.
- Membership renewal is continuing, with 152 Ambassadors renewed so far, raising £1,020 for the scheme.

2 HAV Membership

One long term HAV member will be stepping down at the end of September and some others will follow in the near future. A role description has been produced ready for circulating to networks, and the HAV Terms of Reference has been updated.

3 Hampshire Carer's Partnership (HCP) & Board

Four HAV members represent us on this Partnership, including its Partnership Board. Since the last HAPB meeting, the topics discussed have included:

- CQC regulation 9a explanation. This entitles people to have someone of their choice to visit them in care homes. This is also relevant when going to hospital appointments.
- Carers strategy action plan.
- Carers register – only 25% of unpaid carers are logged with GPs, how can this be improved.
- Four-month wait for carer's assessments. Why not use social prescribers?
- HOAP (Hampshire Older Adults Partnership) led by Matt Hutchinson and Anne Meader. There are 21 people from throughout Hampshire involved.
- PRSB (Professional Records Standards Bureau) social enterprise charity – to ensure standardisation of forms, would like to attend to explain Disability Related Expenses.

3.1 Carers LD working group

Dave Humphries is chair. Items discussed:

- There is hope that with Cllr Bill Withers chairing the LD Partnership Board that there will be some progress and that carers (represented by Dave Humphries) will have more of a voice. Financial Advice Board (FAB) portals were also discussed.
- Mandy Grahamsley, Hampshire presented about the HCC "Shared Lives" program, including its involvement in Respite Care. In her presentation Mandy highlighted that there are 131 long stay clients. There are 66 "Shared Lives" carers. There are 47 clients who experience respite.
- Donna Harrison Head of Younger Adults Adult Health & Care (AHC) and Jason Norum gave an update including:
 - Developments and improvements in Contact, Assessment and Resolution Centre (CART) & Multi Agency Safeguarding Hub (MASH)
 - There are 149 outstanding Care Act Section 10 carers assessments (down from 170), there are no outstanding LD carers assessments
- HIOW Integrated Care Board (ICB) representatives including Tracy Sedgemore, raised issues:
 - A significant focus for the HIOW ICB is LD and health inequalities
 - LD Friendly practices
 - Sensory communication boxes have been distributed to general practices and acute hospitals
 - Reasonable Adjustment Flag project
 - Annual LD Health Checks, what looks good and completing Ardens templates as much as possible
 - Walk-through videos, e.g. x-ray department

3.2 Carers joint implementation group (JIG)

- This group aims to implement the carers strategy action plan
- The next steps include updating procedures relating Care Act Section carers assessments, having a consistent accessible policy around respite care and increasing the number of individuals registered with and coded as carers by their practices.

4 Personalisation Expert Panel/Partnership (PEP)

Our HAV representatives regularly attend PEP meetings. Since the June HAPB, the following topics were discussed:

- Emily Green, AHC Governance and Quality and Improvement, discussed the changes at Adult Health and Care including the retirement of Graham Allen and the appointment of Jess Hutchinson. Emily also discussed the preparations for the CQC inspection.
- Three speakers from the ICB took part in a discussion regarding how PEP could be more involved in co-production with the new ICB. PEP members gave personal examples and our HAV member gave the HIOW ICB design project, Mental Health Charter and others as examples of co-production which the HAPB has been involved with.

5 Recent examples of Co-production

These examples have been collated at the request of PEP. This list will be of value during the Care Quality Commission's (CQC's) forthcoming local authority inspection of Hampshire County Council.

No	Date	Title	Action or outcome
1	May 2015 to date	Hampshire Autism Ambassador Scheme	Autism Ambassadors are spreading the understanding of autism to work and community colleagues, family and friends
2	2018 to date	Autism Ambassador Annual Conferences	Conference enables Ambassadors to meet and share ideas, and listen to inspirational speakers
3	2016	Autism and Mental Health consultation report and film	Online survey, interviews with autistic individuals, discussion of the initial results as a focus group with professionals to discuss their views and perspectives
4	2016 - February 2020	Mental Health and Autism Charter	The Charter is based on four principles for supporting autistic people who require care and support for their mental health
5	2019 - 2020	Autism epidemiology analysis for Hampshire Portsmouth, Southampton & Isle of Wight	Autism epidemiology analysis using Care and Health Information Analytics (CHIA) for Hampshire and the Isle of Wight
6	2021 - 2023	Hampshire's All-age Autism strategy	Hampshire's All-age Autism strategy including six Task and Finish Groups (TFGs)
7	August 2022	Online Regional meeting	Online Regional meeting, with autism leads and others from several South Eastern England local authorities plus Dorset and Wiltshire.
8	2024	Autism and attention deficit hyperactivity disorder (ADHD) Survey, as part of a larger program to update the autism and ADHD assessment pathways	Autism and ADHD Survey Co-design

6 HIOW Autism and ADHD Referral and Assessment Pathway Patient Experience Survey Update

Three HAV members are involved with this survey organised by Nicky Adams, Senior Project Manager All Age Autism and ADHD, Hampshire, Southampton and Isle of Wight ICB. Beth Ford, User Involvement Manager at Southern Health Foundation Trust, has been appointed as co-chair. All three HAV members are in the HIOW ICB Design Autism & ADHD sub-group. All sub-groups will meet soon to review the questionnaire. The next step will be how to circulate the survey and encourage as many people as possible to respond. No launch date yet.

7 Health Inequalities & Core20Plus5

Core20PLUS5 is a national NHS England approach to inform action to reduce healthcare inequalities at both national and system level. It focuses on most deprived 20% of the national population including ethnic issues

and challenges. One HAV member is a Core20Plus5 Ambassador who meets regularly with other HIOW ICB ambassadors. In July, he met with some members of the Hampshire & Isle of Wight Integrated Care Board's Population Health and Inequalities Team. Key issues include:

- How can Core20Plus5 help us develop an improved understanding of the health inequalities experienced by autistic people at a local (place based) level?
- The same methodology could be used to focus on other chosen groups, e.g. dementia, carers, specific protected Equality Act characteristics, etc
- Will it be possible to link at record level from GP records to national data sets and local authority records at a granular level?
- The discussion included the proposed use of the general practice autism register to understand how autistic people encounter and travel through the NHS by analysing Data Sets such as Emergency Care Data Set (ECDS) and Mental Health services Data Set (MHSDS).

On 2nd August 2024, the CQC announced that Hampshire & Isle of Wight ICS has been chosen as one of four test sites for their Integrated Care Systems (ICSs) Engagement and Inequalities Improvement Network.

Our impression is that this programme is something that could be enhanced by the ICS's integration with local authorities, alongside engagement with people and communities to reduce health inequalities.

Our HAV member has already written to the four colleagues, with whom he met on 31st July 2024 to explain that the Hampshire Carers Partnership, Hampshire Autism Partnership Board and Hampshire County Council Personalisation Expert Partnership (PEP) have significant experience in co-production and would be pleased to work with the ICS.

8 Veronica Price, Portsmouth Autism Community Forum

Dr Veronica Price from the Portsmouth Autism Community Forum joined us a guest. The Forum has worked with Portsmouth City Council to set up Room One, a new space managed by autistic people, for autistic people in Portsmouth. The space is a one-stop shop for autistic and neurodivergent adults aged over 18, their family and friends, and the professionals supporting them. All art projects, peer support advice and guidance are autistic led.

The Portsmouth Neurodiversity Profiling Tool is in process of being rolled out during the last few years. It is being audited and is for schools. Its effectiveness is not yet known because it is carried out differently in each school and not enough children have been through it and therefore difficult to audit.

ICS representatives have stated on several occasions that this will mean fewer referrals will be necessary for autism and ADHD assessments. Both Portsmouth Autism Community Forum and HAV are aware that many organisations, including educational establishments and employers, still require documented proof of a diagnosis of autism or ADHD, ideally by an accredited organisation. Our recommendation is that referral for such assessments will still be necessary, although the process may be different as so much structured information will already be available.

9 Hampshire Mental Health Charter for people on the autism spectrum

A re-launch of the Mental Health Charter is being discussed between HAV members and other interested parties such as Catherine Barnard who is keen to extend the charter across the whole HIOW ICS. The aim now is to expand the Charter to all four HIOW county and unitary authorities, and target Mental Health and physical health providers. A working party is being organised. A re-launch event in the autumn is being discussed for later in the year.

10 Online Resource Directory

HAV have distributed a survey to our network released by the Gender Identity Research and Education Society (GIREs) to provide information to support trans and gender diverse people with autism and professionals who support them.

11 Early Help Needs Led Adults sub Group

A HAV member has been invited to this sub-group by Tina Woodcock.

12 Farewell to David Carter

David attended his final HAV meeting in September as he steps down to concentrate on other projects. David has been a member of and significant figure in HAV for 11 years, contributing to many meetings, projects, surveys and the Mental Health Charter, giving many hours of his time voluntarily. He will be sorely missed, and we give heartfelt thanks to him for all his hard work over the years. David will continue to attend HAPB meetings in his capacity as a lead volunteer for the Autism Ambassador Scheme and as Chair of NAS South Hampshire Branch.

13 Local Groups feedback

HAV members continue to be involved or in touch with many autism support groups across the county. The latest information includes:

National Autistic Society South Hampshire Branch (www.shantsnas.org.uk)

The Branch organised 8 successful Wet Wheels trips in July. Upcoming events include a Watercress Line trip and Quiz Night in October and a Winchester Science Centre trip at the end of November.

Starting to plan a possible speaker event in March/April 2025.

All normal groups running fine and have resumed after the summer break.

Autism Support Group in Totton

This group, run by Youth and Families Matter (YFM), a community project of Testwood Baptist Church, is being well attended.

Friends of In Touch (www.friendsofintouch.org.uk)

Continue to support children and young people in their weekly youth clubs, and a young adults' social group. This is the organisation's 20th year and currently has funding from the National Lottery for another 4 years.

The Zone, Farnborough

Zone In sessions for children and their families, once per month and in the school holidays.

Supportive Parents of Asperger Children Everywhere (SPACE) (Havant)

Monthly group that meets at the Heron pub in Leigh Park.

September 2024



“No matter how much you know or understand about a subject, you will always learn more and add to your own knowledge when taught by people with lived experience - so much to gain from just an hour of your time”



Requirement for training: New statutory training for everyone to complete to better support people with learning disabilities and who are autistic.

[NHSE Oliver McGowan website](#)

The set up of the training is as follows;

Tier 1 (people who require general awareness of the support autistic people or people with a learning disability may need) - 90 minute e-learning + 1 hour live online webinar

Tier 2 (provide care and support for autistic people or people with a learning disability) - 90 minute e-learning + full day face-to-face seminar

Tier 2 update: We are pleased to announce we have now partnered with [Impact Initiatives](#) and [Avenues Trust](#) to be our seminar training providers

Seminars will be launching Autumn 2024

Performance update

E-learning completions: 51,596 (81%)

Tier 1 webinars completions: 1790 (11%)

Access and follow the HLOW ICS webpage and social media accounts for updates and information



#OliversCampaign





New autism research opportunities for you!

Exploring money management practices among autistic adults

Type of involvement: Interview

About the project

Researchers at City, University of London, are studying how autistic adults manage their personal finances, such as making payments, managing accounts, and handling household budgets. The research aims to make the space of money management more aligned with neurodivergent needs for better autonomy, agency and well-being.

Who they're looking for:

- People over 18 with a formal diagnosis of autism without intellectual disability
- Have some financial responsibilities (not entirely dependent on someone else to manage their money)
- Comfortable talking to the researcher on a video call.

What they'll ask you to do:

1. Complete a short survey about yourself (5 min)
2. Join a video call to learn more about the research (15-30 mins)
3. Complete a preparation task in your own time (~30 min)
4. Join a research session (90 min) online or in at City University, London: you will work with the researcher to arrange items on a physical or digital whiteboard while talking through topics about finances.

What you'll be offered for your time: You will receive a £50 Amazon voucher for completing the study.

[Express your interest](#)

Autistic young people's experiences of treatment for anorexia nervosa

Type of involvement: Interview

About the project

Researchers at the University of Edinburgh want to talk to autistic young people about their experiences of Family Based Treatment (FBT) for anorexia nervosa. They want to find out what was good about it and what they think could be improved to help people in future.

Who they're looking for:

- Autistic people (formally or self-diagnosed)
- Aged between 14-21
- Who have had Family Based Treatment for Anorexia Nervosa.

If you aren't sure if this is the type of therapy you've had, you can still get in contact with the researchers.

What they'll ask you to do: Eligible participants will be invited to an online interview to talk about their experience of FBT (30mins - 1hr) using video or written chat. Participants under the age of 16 will need parental approval to take part.

What you'll be offered for your time: Participants who take part in an interview will receive a £20 Love to Shop / Amazon voucher.

Contact: vanessa.haugaard@nhslothian.scot.nhs.uk

Take part

Reading Between the Lines

Type of involvement: In-person research

About the project

Researchers at the University of Bristol are studying how autistic and non-autistic people understand text when reading. This work will increase the scientific understanding of how text is processed by different people and inform inclusive education practice.

Who they're looking for: The researchers are seeking adults with an autism diagnosis and also non-autistic adults to take part. All participants must also:

- Be aged 18 years +
- Be native English speakers
- Have no formal diagnosis of a learning difficulty (e.g., dyslexia)
- Be able to come to the University of Bristol

What they'll ask you to do: Taking part would involve silently reading text while your eye movements are monitored, along with completing a range of other tasks e.g., solving puzzles and completing questionnaires. This will take up to 5 hours. You can participate in one full day, or two half days.

What you'll be offered for your time: You will be paid up to £50 for your time, along with any reasonable travel expenses.

How to take part: If you are interested in taking part please email Dr Nick Martin for more information via rbl-project@bristol.ac.uk.

Find out more

Autism in Affinity Spaces - Interest-driven social media

Type of involvement: Interviews

About the project

Researchers at Queen Mary University of London want to explore how autistic young people use social media to engage with their interests. Along with how advances in digital communication research can shed light on communication, the importance of interests for wellbeing, and social relationships in these groups, to make online spaces more inclusive.

Who they're looking for:

- People aged 16-26
- Live in the UK
- Identify as autistic.

They are particularly looking to recruit participants who identify as BAME, nonspeaking, or low-speaking. You should have some experience with using social media.

What they'll ask you to do: You will take part in two interviews (45-60 minutes each) via a medium of your choice (e.g., Zoom, email, online chat). We'll talk about your experience with using social media to engage with your interests. Between these two interviews, a researcher will follow you on a social media platform of your choice for 4 months and collect some of your posts to talk about together in the second interview.

What you'll be offered for your time: £60 in high street vouchers.

Contact Jessica Aiston, j.aiston@qmul.ac.uk if you have questions.

[Register your interest](#)

Exploring sense of belonging in autistic university students

Type of involvement: Interview

About the project

Researchers at Birmingham University are currently exploring the sense of belonging in first-year autistic university students to understand the barriers and facilitators to feelings of belonging.

Who they're looking for: Adults living in the UK with a formal diagnosis of Autism Spectrum Disorder, who have attended or are currently attending university. It is likely people aged 25 and under will have the clearest memories of being in their first year of university. However, please get in touch if you'd like to talk about that period and are older.

What they'll ask you to do: Complete a demographic questionnaire followed by a one hour, one-to-one interview. This can be either face-to-face at the University of Birmingham, or via Zoom.

What you'll be offered for your time: £15 voucher.

How to take part: To register your interest email Emily Taylor at eat223@student.bham.ac.uk.

Experiences of caring for a child with ARFID

Type of involvement: Interview

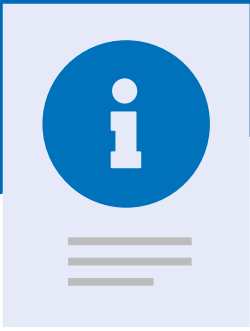
About the project

Avoidant/Restrictive Food Intake Disorder (ARFID) is a relatively new diagnosis that often co-occurs with autism, and there is limited research on what causes it to occur, how to assess for it and the most appropriate, evidence-based interventions. This research by a trainee clinical psychologist will take an in-depth look at the caregiver journey, from first noticing differences in eating to getting support for their child and themselves.

Who they're looking for: Adults over the age of 18 with a child aged 11 or younger who has a diagnosis of ARFID.

What they'll ask you to do: An online meeting will be arranged to tell you more about the research and then you will be emailed some forms to complete, including a consent form. The interview will take place online at a time most convenient to you and the lead researcher. It should take around an hour and a half to complete and the researchers would like to audio record your responses.

How to take part: Email Gemma to express an interest daceyg2@uni.coventry.ac.uk.



Inclusion Hampshire Quarterly Information Session

Three dates available to choose from:

Thursday 18th July 2024

Thursday 17th October 2024

Wednesday 15th January 2025

Link for registration: [Thursday 18th July 2024](#)

Link for registration: [Thursday 17th October 2024](#)

Link for registration: [Wednesday 15th January 2025](#)

The session will provide information about our service in Hampshire, outline our referral process and treatment options, as well as provide some basic drug and alcohol awareness training.

This session is aimed at professionals working with people who may benefit from drug and alcohol treatment/support, or staff members from our partner agencies who would like to expand their knowledge around drugs and alcohol.

