

# NEURODIVERSITY IN GLOUCESTERSHIRE

Autumn 2023  
ISSUE 2



News and updates from your local Autism Partnership Board



**Welcome to Issue 2 of the quarterly bulletin from your local Autism Partnership Board.**

**In this issue you can find updates from our latest board meeting, as well as lots of interesting news, updates and opportunities from across our wider member network.**

As Co-Chairs of the board, we are committed to helping our members work together to achieve a shared goal of improving the lives of all neurodivergent people in Gloucestershire. As part of this, we are interested in connecting with other Autism Partnership Boards across the South West, with a view to sharing best practice around board governance and leadership while also facilitating co-production within and between each region.

We will be working on this over the coming quarter, so if you have any useful links to share with us, please do contact us at [neurodiversity@gloucestershire.gov.uk](mailto:neurodiversity@gloucestershire.gov.uk).

*Liz Bell and Andrew Cotterill*

*Co-Chairs of Gloucestershire Autism Partnership Board*

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### New funding announced for NHS autism and ADHD assessment services

NHS Funding has been secured by local commissioners to expand and improve both children and adults NHS diagnostic services for autism and ADHD in Gloucestershire.

The funding will support the development of combined autism and ADHD services for adults and children by building staff capacity and making better use of existing resources by combining existing separate pathways.

Noor Al-Koky, Interim Senior Commissioning Manager for Adult Mental Health, Advocacy and Autism in the Integrated Adults Commissioning Hub at Gloucestershire County Council, said:

“This is a significant development and will take place in stages with a long-term goal of increasing the number of assessments available and reducing waiting times. The Partnership Board will be updated on progress in the coming months.”



### Educational Psychology Service set to offer support to every school in Gloucestershire

Educational Psychology Service (EPS) are moving from a traded time model to provide an allocated Educational Psychologist (EP) for each school (maintained and academy). This is to provide equity of service and a focus on early identification of needs and support to schools and children. Therefore, schools no longer need to purchase traded time through a subscription model. This exciting opportunity allows the EPS to offer a free at point of delivery core offer.

Each school has a named Educational Psychologist. Each EP plans their work with schools and settings and support through the Code of Practice for Special Educational Needs.

The EPS are also developing a programme of training and development including the ELSA programme and promoting language friendly provision and workforce development through the ELKLAN programme.

### Call for neurodivergent volunteers to advise on peer mentoring pilot

Inclusion Gloucestershire is seeking volunteers to join a new steering group to inform and shape the delivery of its pilot peer mentoring programme for late-identified neurodivergent adults.

The ZIG/ZAG Peer Mentoring Project is testing a new, 1-2-1 approach to support, through which people who are exploring their neurodivergence will be matched with trained peer mentors who can offer non-hierarchical, ND-affirming support.

Chris Woolner, ZIG/ZAG Peer Mentoring Project Manager at Inclusion Gloucestershire, said:

“We’re keen to ensure that delivery of this project is informed by a diverse range of neurodivergent experiences and perspectives, so people from under-represented groups or marginalised communities are strongly encouraged to apply.”

Email [chrisw@inclusion-glos.org](mailto:chrisw@inclusion-glos.org) for more details.

### Short Breaks provision for children and young people

**Barnwood Trust has awarded one-year funding to six local organisations to deliver Short Breaks projects, two of which are aimed specifically at neurodivergent children and young people.**

‘Short Breaks’ are activities or opportunities that allow children with additional support needs to spend quality time away from their families and to grow in confidence, autonomy and independence. A key aim of the new Barnwood programme is to develop some best-practice principles for the delivery of Short Breaks in Gloucestershire.

The organisations that have received funding include ADHD Hub Gloucestershire, which will be expanding its peer support offer for children and young people with ADHD, and Can’t Sit Still, a participatory arts charity that will be running two new, weekly creative clubs for autistic girls and non-binary young people in Cheltenham.

**More information about Short Break provision in Gloucestershire can be found in the ‘Guide to Short Breaks’ booklet from Active Impact.**

“At the ADHD Hub Gloucestershire CIC we’re excited to join Barnwood Trust in this innovative Short Breaks learning project. Creating activities that disabled children, young people, and their families want and need by listening to their expert lived experiences. Together, we’re tailoring desired activities in practical and innovative ways that fit each families requisite.”

*Zaphira Cormack, ADHD Hub Gloucestershire*

**More info at: [www.adhdhubglos.org](http://www.adhdhubglos.org)**

“Our ‘Being Me’ project will support autistic girls and non-binary young people aged 11 – 25 in Cheltenham to learn, grow, and connect through participation in weekly creative activity sessions in an inclusive and neuro-affirming space. In this safe, trusting, relaxed environment autistic young people will be able to unmask and explore feelings and ideas safely and creatively, while also building confidence and resilience.”

*Jay Haigh, Can’t Sit Still*

**More info at: [www.cantsitstill.net/being-me](http://www.cantsitstill.net/being-me)**

### Helping neurodivergent people to understand their rights to social care

**Would you like to know more about what social care is, what your rights are and what should be covered by adult social care assessments?**

Social care services provide support to people with learning disabilities, physical disabilities, people with long term health or mental health conditions, older people and autistic people. This support can cover practical activities, personal care, and social support to live their lives as fully and as independently as they want.

Gloucestershire-based charity, Access Social Care, is offering free talks for groups of people who may have social care needs, for their carers, or for organisations that support people.

This can be via an informal talk, or through a full training session on the Care Act and/or on using the Access Social Care online advice tool.

**To find out more, email Jacky Martel at Access Social Care: [jacky.martel@accesscharity.org.uk](mailto:jacky.martel@accesscharity.org.uk)**



# Transforming Care

**In 2015, the UK Government promised "homes not hospitals" when it launched its Transforming Care programme. But targets to reduce the number of patients in hospital settings by nearly a third within five years were not met, with a reduction of just 13% being achieved by 2020.**

By 2021, more than 2,000 people with learning disabilities and/or autism were still being detained in inpatient units in England. Analysis by the BBC revealed that 350 of these had been detained for more than a decade, and 100 for more than two decades. These shocking findings coincided with the conclusion of a parliamentary review on long-term segregated care, in which the chair of the cross-bench review committee told the House of Lords that it was time to "end the scandals" and give people back their lives.

Another two years later, still very little progress has been made. While the overall number of people being detained has decreased, the rate of detention of autistic people continues to rise. In 2015, autistic people made up 38% of the psychiatric inpatient population in England; now, nearly two-thirds (63%) of patients in mental health hospitals are autistic, with the latest NHS figures showing that 1,290 autistic people are currently being detained (as of July 2023).

The government's latest commitment is to reduce the number of people with a learning disability and autistic people in inpatient units by 50% by March 2024. But analysis by Mencap suggests that based on current estimates, the government is likely to miss this target by at least 4 years.

Mencap is calling on the government to make major improvements to its national action plan - including by ensuring local areas have enough funding to build the right community support.



## What do best practice guidelines say?

NICE guidelines recommend that autistic children, young people and adults should be admitted to inpatient units only if assessment and care planning show that their needs cannot be met safely in the community, and when all possibilities for doing so have been considered and exhausted. The guidelines also say that in cases where an inpatient placement is needed, local authorities and clinical commissioning groups should provide this as close as possible to where the person usually lives.

## What's happening in the South West?

Of the NHS England commissioning regions, SW England has the second-lowest proportion of inpatients with learning disabilities and/or autism. However, NHS data shows that in July 2023, 27% of inpatients had travelled up to 10km for their care or treatment, whilst approximately 34% had travelled over 50km. The data also shows that even when people are discharged from hospital, they often go straight into other treatment settings. Of all the inpatients who were discharged from a hospital during July 2023, only 72% were returned into the community.

### CASE STUDY: The Small Supports Partnership

The Small Supports Partnership was formed five years ago by a group of organisations led by the National Development Team for Inclusion (NDTi) and the Local Government Association, in response to the lack of progress that had been made by the Transforming Care programme.

The partnership includes small support providers Beyond Limits, C-Change and Positive Support for You, each of whom have adopted a community-based, person-centred approach to supporting adults with autism, learning disabilities, and/or mental illness to live outside of secure settings.

The partnership works with statutory authorities across England to identify local priorities and to develop and enhance existing provision in line with the Small Supports ethos and approach. They are currently working with 11 local agencies at varying stages of development, with plans to work with another 20 over the next three years.

**For more information about how Small Supports work, visit the NDTi website at: [www.ndti.org.uk/change-and-development/small-supports](http://www.ndti.org.uk/change-and-development/small-supports).**



### Transforming MH inpatient advocacy in the South West

Last year, Inclusion Gloucestershire were commissioned by NHS England to evaluate the support and advocacy available in the South West to people with learning disabilities and autistic people who are or were inpatients in mental health hospitals for 2 years or more.

The Small Supports Partnership was one of four service providers highlighted in the final report as being examples of best practice, alongside Independent Supporters, SWAN, and the Citizen Checkers Inpatient Peer Advocacy programme.

The report also identified a number of barriers to the successful provision of support, including advocates being sent away from hospitals (often due to concerns about inpatient behaviour), a lack of professional skill and/or capacity for Life Planning, a lack of suitable community support, and the geographic considerations that limit or prevent growth of peer advocacy programmes.

To explore the progress made since the evaluation was conducted last year, and to reflect on what work is left to do, the NHS England Learning Disability and Autism Programme Team recently held an event that brought together service users, advocates, healthcare professionals, and commissioners.

More information about the discussions at this event will be published soon via NHS England.

***“We believe that nobody should be detained in psychiatric hospitals or ATUs for long periods of time, and that everyone has a right to a home in the community.”***

*Vicci Livingstone-Thompson  
CEO, Inclusion Gloucestershire*



### SEND Support for Families: Local Offer for Parent & Carers in Gloucestershire

In the last issue, we highlighted the new and improved website for the Local Offer, which highlights the support that is available in Gloucestershire for parents or carers of children and young people with autism or ADHD.

Since then, a new SEND Information Development Officer has been recruited to further develop the website and to make sure that the content is correct and up to date. If you would like to see any information added to the Local Offer website, contact [localoffer@gloucestershire.gov.uk](mailto:localoffer@gloucestershire.gov.uk).

### What (not) to say when someone tells you they have Tourette's Syndrome

At our latest Autism Partnership Board meeting, we were fortunate to be joined by Bernadette Wilson, who spoke about the challenges faced by her family since her son was diagnosed with Tourette's Syndrome six years ago. One of the points Bernadette made was about how frustrating it is when people ask the same questions again and again, based on misinformation about what Tourette's is and how it presents.

That's why we're sharing this fantastic short film made by charity Tourette's Action, featuring young people with Tourette's Syndrome (and their parents) reacting to some of the most common stereotypes and misconceptions that exist around how this little-understood syndrome can present.

**Watch the video on YouTube via: [tinyurl.com/35nrs7f4](https://tinyurl.com/35nrs7f4)**



### Six key principles for developing ND-informed services and pathways



Earlier this year, Scotland's National Autism Implementation Team (NAIT) published a set of key messages, co-produced by neurodivergent adults, to inform the development of future neurodevelopmental pathways.

While this resource was originally funded and developed in Scotland, it offers a useful starting point for any commissioners and professionals looking to adopt a more progressive, neurodiversity-affirming approach, wherever they are based in the UK.

**The full list of key messages is presented on the following page.**





# Key Messages for supporting neurodevelopmental differences in adults

## 1. 'Nothing about us without us'

Meaningful co-production is central to developing a whole systems approach neurodevelopmental pathway that works for all people who access it

## 2. Difference not deficit

Neurodiversity is a positive thing in society. A strengths based approach changes how we communicate about people, communicate with people, make adjustments and what services focus on

## 3. Environment first

The basis of all effective support is having the right expectations and adjustments in the physical and social environment in every day naturally occurring settings of home, education, employment and the community

## 4. Diagnosis matters

People seeking or receiving neurodevelopmental diagnoses tell us diagnosis matters in so many ways – understanding and celebrating personal identity, understanding past, present and future experiences, accessing relevant information and a community of peers, informing which supports and interventions are right for them

## 5. Language matters

A range of preferences exist and one size does not fit all – we can listen and adapt the language we use to reflect individual and community preferences

## 6. A neurodevelopmental lens

We can expect to meet people with neurodevelopmental differences in everyday life and in mental health services. We can approach everyone with an inclusive and positive mindset and the right lens on support we provide

# Dates for your diary

**Every quarter, we highlight a few of the support groups and meet-ups happening across Gloucestershire.**

## **Your Voice SW Neurodiversity Group**

Meets online on the first Thursday of every month from 18:00-19:30. Contact Sammy Roberts on [sammyr@inclusion-glos.org](mailto:sammyr@inclusion-glos.org)

## **APB Autism Lived Experience Group**

Meets online on the first Monday of the month from 14:00-15:30. Contact Andrew Cotterill on [Andrew@Cotterill.info](mailto:Andrew@Cotterill.info)

## **Churchdown Autism Group**

Meets at Churchdown community centre on the first Thursday of the month from 14:00-15:30. No need to book, just come along!

## **Wotton Area ND Peer Support Group**

Meets at The Keepers, GL12 7BD, on the second Thursday of every month from 09:30-11:00 and the last Wednesday of every month from 19:00-21:00. For more information contact [wottonnd@gmail.com](mailto:wottonnd@gmail.com)

## **Community Autism Support and Advice (CASA) support groups and drop-ins**

Various locations - for more details visit [www.independencetrust.co.uk/CASA](http://www.independencetrust.co.uk/CASA) or email [info@independencetrust.co.uk](mailto:info@independencetrust.co.uk)

## **Gloucestershire Parent Carer Forum 'Listen To Me' Social Meet-ups**

Various locations - for more information visit [www.glosparentcarerforum.org.uk](http://www.glosparentcarerforum.org.uk)

## About Gloucestershire Autism Partnership Board

The Gloucestershire Autism Partnership Board brings together organisations and people with lived and professional experience of autism and neurodivergence to oversee the implementation of the local Autism strategy. Our local priorities reflect the six overarching themes of the National Autism Strategy:

1. Improve understanding and acceptance of Autism
2. Improve Autistic children and young people's access to education and support positive transitions into adulthood
3. Support more Autistic people into employment
4. Tackle health and care inequalities for Autistic people
5. Build the right support in the community and support people in inpatient care
6. Improve support within the criminal and youth justice systems

## Want to join us?

The board meets online once per quarter. If you would like to come along to our next meeting, please send a request via email to:

[neurodiversity@gloucestershire.gov.uk](mailto:neurodiversity@gloucestershire.gov.uk)

You can find more about what happens at our meetings, and view minutes of previous meetings, at:

[www.gloucestershire.gov.uk/health-and-social-care/disabilities/autism-partnership-board](http://www.gloucestershire.gov.uk/health-and-social-care/disabilities/autism-partnership-board)