NEURO KEY
An Alliance supporting people with neurological conditions

.

20th Anniversary

2005 - 2025

Development of work and impact

Neuro Key
Registered Charity 1119043

Contents

Forward

This year we celebrate 20 years of our charity, Neuro Key. Neuro Key is a charity serving the needs of over 100,000 people with a neurological condition in the North of England. Most of our Trustees and members have knowledge, expertise and lived experience of neuro-disability and this drives our work and impact. We are formally recognised as a Disabled People’s Organisation and Disability Confident Employer with expertise in 33 neurological conditions, impairments, disabilities and neurodiversity. Our work includes engaging with and delivering advocacy, peer support and guidance for individuals and families to raise awareness of the needs of neuro-disabled and neurodiverse people, across their lifespan, in the NHS, social care services, schools, colleges, local and government departments.

We are published authors in partnership with Teesside University to improve opportunities for disabled people to take part in informing and influencing future generations about neuro-disability and neurodiversity. If people living with a long-term neurological condition are to receive the quality and level of support and care they need, it is essential that care commissioners, commissioners of service, law makers, providers and regulators know more about the lived experience of people with neuro-disabilities.

There needs to be a better understanding of the relationship between the impact on the individual and their families and the components that need to be in place for the provision of equitable and consistent policies and care practices. There needs to be an acknowledgement that there are sometimes tensions that exist in the relationships between people working in and people using care and NHS services due to policy and process not being aligned with needs.

Neuro Key has aimed to not only enable solidarity between organisations but improve understanding about the commonalities between neurological conditions. In-so-doing, we strive to include neurological conditions on Long Term Condition agendas due to longer term disability. Through participatory research and lived experience narratives, we have added impetus to statutory sector initiatives, policy and professional non-medicalised knowledge. This is the only way to enable a future for people living with a disability to settle in an inclusive society, as equal citizens and with full and enforceable civil rights.

Therefore, we are driven to continue to work with carers, professionals, academics, researcher’s, politicians and people with lived experience of long-term neurological conditions to improve professional knowledge and influence inclusive health, social care and education service delivery in the future.

David Mudd
Chairman of the Board of Trustees

Background

In 2005, the founding Chairman, Dr Anthony (Ginger) Butler wanted the Tees Valley Durham and North Yorkshire Neurological Alliance Charity to be about 'life with …., not suffering from'. He felt if we did a good job, there would be no need for us to exist in a decade.

Two decades later, the Charity became Neuro Key to reflect our expertise in understanding and resolving the daily difficulties that beneficiaries experienced. The strategic environment transformed from regional networks and Primary Care Trusts to the NE Integrated Care System (ICS) and Integrated Care Boards (ICB). The changes aimed to drive a fundamental shift from care-done-to, to a collaborative partnership between patient, caregiver, voluntary sector and NHS services to improve patient outcomes.

Since inception, Neuro Key focus has been to enable self-management and translate technical jargon into control, choice and outcomes the person needed. We have stayed steadfast to our core principle, our work must be anchored in the voices of our 1200+ beneficiaries to address barriers, provide evidence to policy-makers, help navigate fragmented services and problem-solve to leave no-one behind. Over the last decade, demand for our expertise has averaged an increase of 10% a year but our funding remains constrained. We do not have statutory sector funding.

We aim to reduce assumption, intolerance and negative life impact about disability and mental health and wellbeing. We include caregivers as equal partners in the life-long journey managing neurological conditions, injuries, disabilities and neurodivergence.

In 2021, the World Health Organisation (WHO), identified neurological conditions as the leading cause of ill health and disability, worldwide. The overall amount of disability, illness and premature death, known as disability-adjusted life years, (DALYs) caused by neurological conditions has increased by 18% since 1990.

In October 2025, the WHO issued a report on the 'Global status of neurology' to highlight the substantial inequalities in neurological care, particularly referring to the stigma, discrimination and burden of disability poverty impacting people's lives.

In real terms, developments have stagnated from 2012 with a tangible lack of service development or non-medicalised awareness of neurological need. In 2015, the national Neurological Alliance* reported just 14.7% of CCGs in England had assessed local costs relating to the provision of neurology services, rendering the neurological community increasingly marginalised and isolated from mainstream services. In October 2025, an FOI* request response defined no breakdown of neurological services values other than, 'Contract values are part of the overall block contract with the Trust'. NENC ICB does not dissect budgets to show rehabilitation services or specifically anything around neurological conditions.

In 2023, Neuro Key lobbied five Tees-wide Borough Councils to ask what post-covid developments were being undertaken for DALYs and Joint Strategic Needs Assessment metrics for neurological disability. There was no response.

For twenty years we have fostered a network of neuro-informed peers to deliver advocacy, education and research with pan-neuro peer support, regardless of the label of condition or disability. Our involvement in regional strategic developments and our narratives of lived experiences as learning resources promotes common purpose across different neurological conditions, medical disciplines and public sector agencies.

Through these mechanisms, we prepare people with condition literacy, improve communication skills to build confidence, self-management and reduce isolation by accessing social opportunities such as peer support or volunteering for participatory research options.

Launched in 2013, our branding has stood the test of time and is recognised across the region. The circle of multi-coloured strands represents the numerous neurological conditions with the strands representing neurons in the brain. The white dots and single strand represent the structural, biochemical or electrical malfunctioning in the brain or spinal cord which results in a neurological condition.

This account follows on from our work 2005 – 2015 for our 10year Impact report.

Feedback from members, stakeholders and beneficiaries

‘It has been inspiring to work with Neuro Key over the last twenty years. Their commitment to promoting and embedding lived experience in research has led to the development of a self-management programme and peer researcher training that are truly coproduced with people living with neurological and other long-term conditions. Neuro Key has always understood the need for integrative, holistic approaches to support people living with neurological conditions, which place equal value on the physical, psychological and social determinants of health and wellbeing. Their partnering on research projects is contributing to the evidence base and raising awareness of the need to embed psychosocial support early in care pathways to reduce the risk of people with neurological conditions slipping into mental health crises and disability.

I'm excited to see the impact Neuro Key will have over the next twenty years.’

Dr Stephanie Kılınç
Senior Lecturer in Psychology
Registered Health Psychologist
Department of Psychology and Social Work
Teesside University

‘Neuro Key have done such a fantastic job of raising awareness and supporting real change, which I hope continues well into the future.
Jo’s contribution to the VCSE Partnership Programme is hugely appreciated – she provides insights, intelligence, sharing of good practice and resources, as well as constructive challenge relating to the health system, all of which are highly valued and incredibly important’.

Lisa Taylor
VONNE Health and Wellbeing Programme Director
VCSE Partnership Programme lead
NENC ICB VCSE representative

‘I am very proud of having been involved with Neuro Key. It is an organisation that lives and breathes the importance of collaborative working and the power of group action. The material that it provides is practical, helping ordinary people improve their lives, in an inclusive manner. This is apparent from, for instance the "My Life Tool" landing page’.

Ben Townsend
STEWARTS Law - Leeds
Partner, Head of Personal Injury
Co-founder in 2005
Trustee Headway Teesside

‘The scale of progress and partnerships this year really comes through’.

Judith Eberhardt
Professor of Psychology and Public Health Equity
Department of Psychology
School of Social Sciences, Humanities and Law

Over the past decade I have got to know the work of Neuro Key and the force for good that their mission promotes. Jo Cole is singularly the most relentless advocate I have ever met, who seeks to create positive change to improve the lives of people with neurological conditions. Jo has been a Foetal Alcohol Spectrum Disorder (FASD) champion from the moment our paths crossed. She immediately understood the impact of and realised that those with FASD, and their families, were a forgotten and overlooked section of society. Her support in raising awareness of FASD, in every aspect of her sphere of influence, has been impressive. Jo's support not only with FASD, but also her support to me personally as a lone worker on this topic have helped to sustain me and my work. The progress around FASD could not have been made without the efforts of Neuro Key.

Maria Catterick
FASD Network UK

As someone who has been involved with Neuro Key and the team for many years, I am grateful for the opportunity to express my support for this wonderful organisation. The gains they have made for individuals are tremendous both in practical ways and by raising awareness of the very many difficulties people with neurodivergent conditions face.

For my part I will always use any opportunity as an MP to further the work from sponsoring student awards to raising awareness in the House of Commons.

Andy McDonald

Andy McDonald MP
Middlesbrough and East Thornaby

‘You have shown extraordinary dedication as an advocate over many years.’

Luke Myer MP
Middlesbrough South and East Cleveland

“I express my admiration at the work Neuro Key is doing to improve outcomes for youth with neurological conditions in later life”.

Anna Turley MP
Redcar and Cleveland
Lord Commissioner of the Treasury

Peer group feedback

“Neuro Key has been an essential partner for our pain group, offering a space where lived experience is valued without judgement. Their collaborative approach helps us navigate the realities of neuro-disability with honesty and dignity. Together, we’ve been able to highlight the day-to-day challenges our members face while celebrating the strength that comes from being truly listened to.”

“Neuro Key is an amazing charity. I wish I was able to find out about it sooner. I have lived with neurological conditions for over 20 years. I finally feel like I’ve found a safe space where I feel heard and understood. Neuro Key is our voice and all the hard work that goes on in the background has ensured this. I am so thankful for all the hard work and ongoing support”.

“I would like to thank Neuro Key for all the hard work over lots of years and their community member, the Pain friendship group. When I was asked at the hospital seeing my last Consultant, I explained how I cope with all my conditions which are numerous, my everyday living. I replied in a few words, Neuro Key and the Pain group, " Why " he asks? Because without either I would feel "Alone", without the help and support I get from these fantastic organisations and the leaders giving of their time and understanding. After our Pain Management course at hospitals, we're out in the big wide world on our own trying to navigate the best we can. These leaders understand the difficult life-balance that people with neurological disability and chronic pain do, day in, day out”.

“I am no longer unemployed. I am a Peer Researcher thank you”.

“The Tees Valley Durham and North Yorkshire Neurological Alliance
changed the name to Neuro Key in a ballot by conference delegates in 2017.
User voice at its best.
The vote was unanimous because the Charity is KEY to raising awareness of what our lives are really like, the challenges, the isolation, combatting ignorance and even hostility because we do not fit regimented tick boxes”.

“Services have become incredibly insular. As a caregiver, you must be all things to everyone else, your own needs don’t count. You feel drained when facing too many challenges. There must be better recognition of Neuro Key that instinctively go the extra mile to help people when they have been diagnosed with a neurological condition. Medical appointments twice a year are a tiny part of the care trudge round services trying to get someone to listen. There is no quick-fix.
We need better consideration for what every day looks like”.

“The politics, media and especially social media have disabled people living in fear. Neuro Key help you feel a human being that matters, set against a society that seems to feel entitled to call you names and mock your disability”.

Networks and stakeholders

Neuro Key has gone beyond the immediate funding transaction/reporting for 20 years to add meaningful social value, taking a two-sides-of-the-coin approach that provides a listening ear for beneficiaries and direct investment in their lived experiences. Through disseminating evidence in regional networks, we have aimed to strengthen a more collaborative, learning and sharing resource to enable fit-for-purpose service design and delivery.

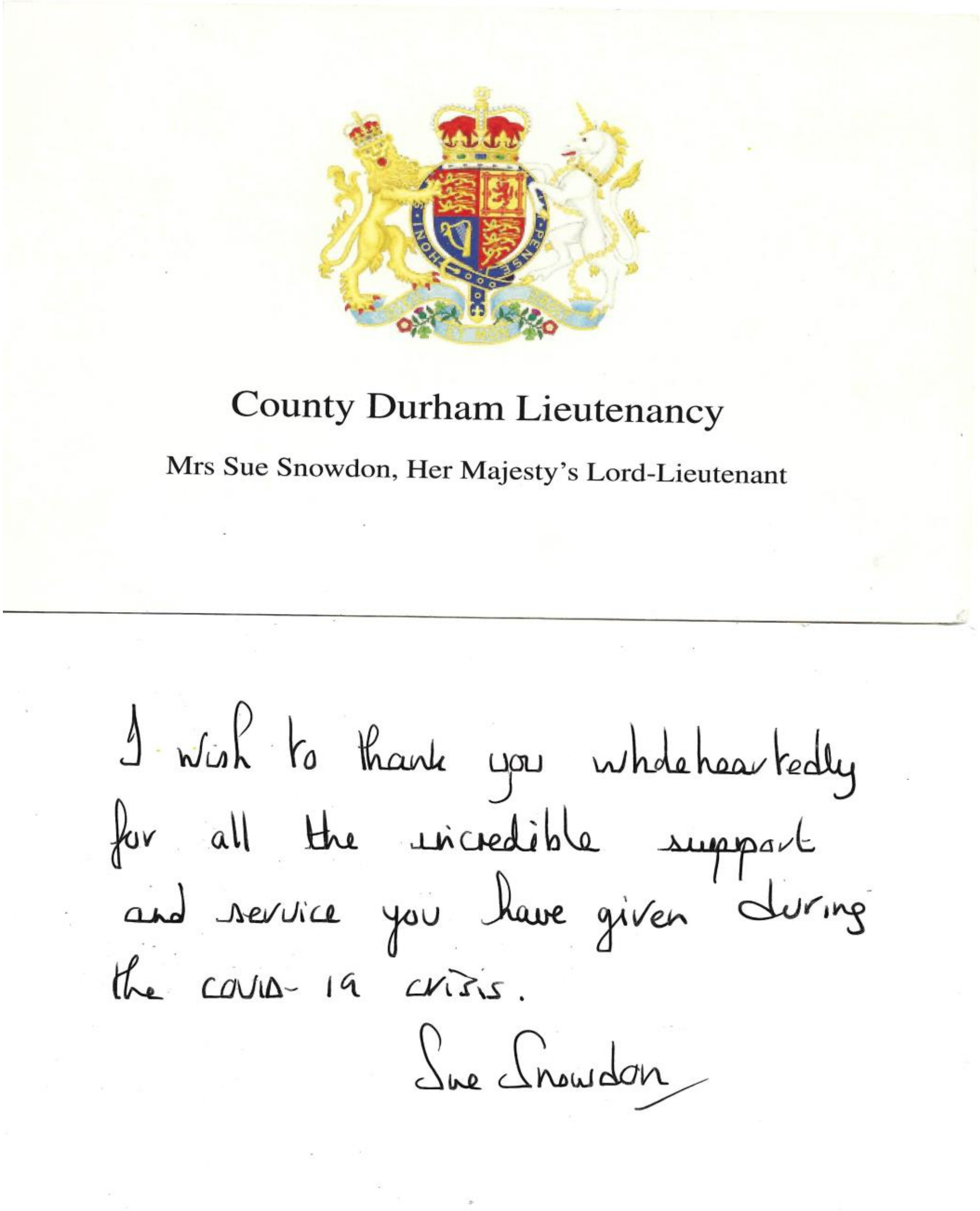
Neuro Key have sustained two multi-neuro peer groups and support the needs of community member, the Pain friendship group. These groups are participants in education and research, are enabled to voice lived experiences and grass-roots knowledge to students, organisations, regional and national questionnaires, surveys and participate in research.

With Trustees, members, donors, beneficiaries, peer supporters and network colleagues we reach over 1,200 people through telephone, website contact page, email and our quarterly Neuro Bulletin. In 2015, the strategic environment in which the Charity operated included;

- North East Strategic Clinical Network (NESCN)
- Involving People Forum (SCN)
- Tees-wide Neuro Forum - NHS
- Care Act Reference group - Middlesbrough Voluntary Development Agency
- Strategy and Development - Evolution – Darlington
- Durham University (Queens and Wolfson campuses) Stockton on Tees

In the last decade, the political narrative strengthened the role of Charities in community service development. Neuro Key has developed working relationships with and contributes to networks and information cycles for;

- Newcastle, Sunderland and Teesside Universities
- Community Mental Health Framework - strategic development
- VONNE partnership - Mental Health Network
    - Neurology Network
    - Representative on the NENC VCSE Partnership Forum
    - Carers network
    - Learning disabilities, Autism and Neurodiversity
- NENC ICS - North East and North Cumbria Integrated Care System
- NENC Provider Collaborative
- NHS Employers/National Engagement Services (NES) for NENC plus Yorkshire and Humber regions on neuro-disability and neurodivergence
- Difference North East - disability rights and accessibility



County Durham Lieutenancy

Mrs Sue Snowdon, Her Majesty's Lord-Lieutenant

I wish to thank you wholeheartedly for all the incredible support and service you have given during the covid-19 crisis.

Sue Snowdon

In May 2021, we received this acknowledgment of the support we offered to our beneficiaries during Covid lockdown. We delivered a 12 hour per day portal across our network to help with isolation and accessibility difficulties. Across the Tees region, we confirmed vulnerability or disability via letter or phone call to 18 organisations, GP's, supermarkets and pharmacies to reduce the impact of queueing for anyone with a mobility disability or caring responsibilities.

Our team collaborated daily on issues and were able to prevent a suicide after statutory services needed 3 days to respond to a crisis. We coordinated a support network within minutes of concern being raised, social contact, phone calls and the person is now an integral member of our network.

Progress and impact

Government Policy and change

The loss of strategic networks and the National Director for Neurology in 2016 has defined ongoing decline in service delivery for people with neurological conditions in the last thirteen years. Loss of training budgets to reduce staff costs and reduction of service capacity has led to a loss of corporate skill, knowledge and understanding of the reality of living with a life-long neuro-disability. We have been resolute about using our expertise for the good of all, sustaining a *'Creative Commons'* approach with Teesside University and all our publications to nurture a learning and sharing environment for students in Health, Education, Psychology and Social Care modules.

Impact

In 2018, with Dr Stephanie Kilinç from Teesside University, we presented to the British Psychological Society Division of Health Psychology conference and achieved our first peer review for the publication – 'Finding Meaning and Purpose': A self-management Framework for long term neurological conditions.

The framework was developed by research participants with lived experience of a wide range of long-term conditions, including neurological disability and subsequently, the self-management programme and My Life Tool was developed. Teesside University and Neuro Key are co-authors – www.mylifetool.co.uk

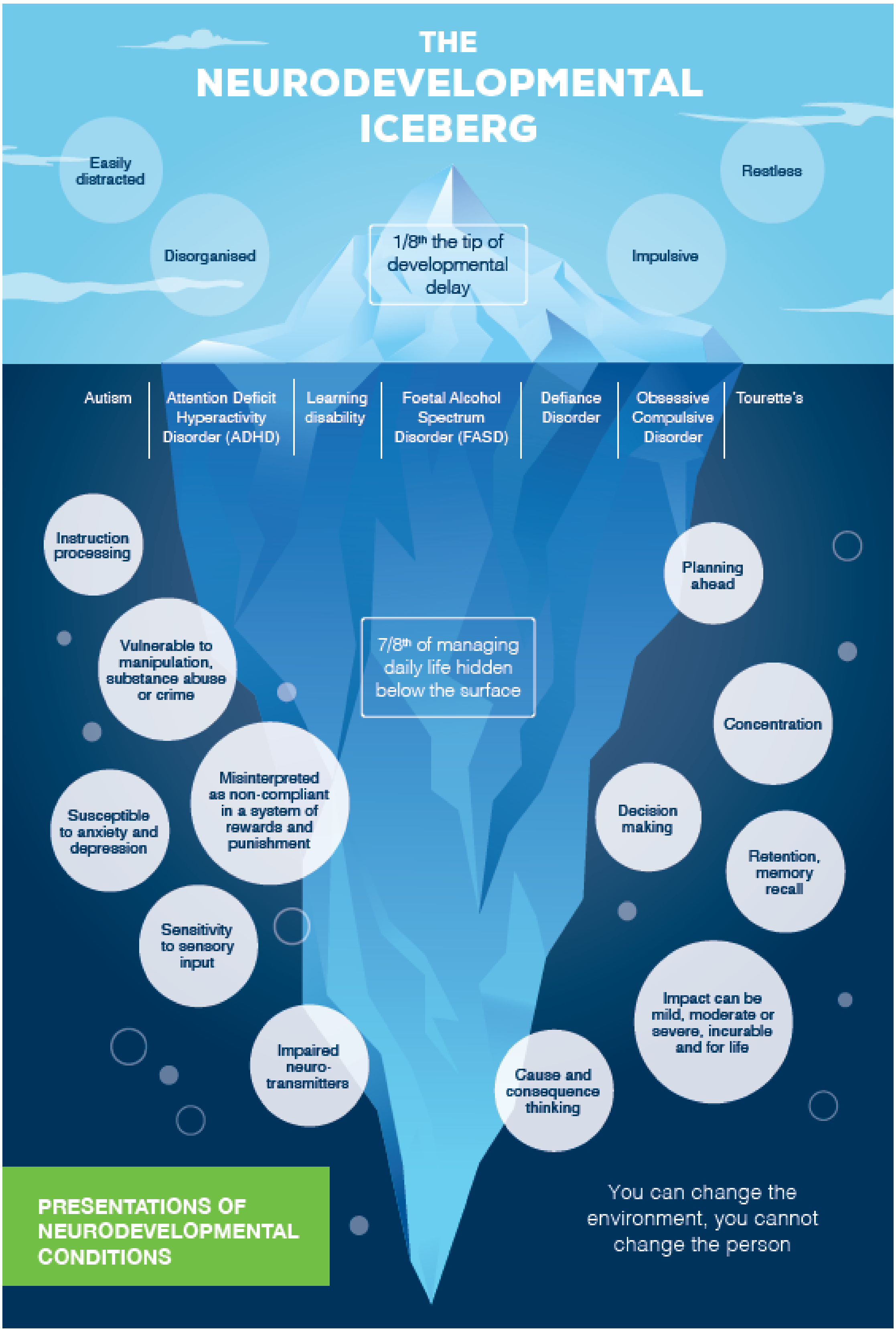
From 2021-23, work for Middlesbrough, (Middlesbrough Council) and Stockton (Tees, Esk and Wear Valley Mental Health Trust, TEWV) Resilience projects showed that schools were ignoring FASD by relying on powers of labelling young people as disruptive, using exclusion to manage pupils' behaviours to avoid impact on OFSTED inspection ratings. Since 2023, we have;

- Enabled the Tees-wide Virtual School for Fostering and Adoption services to regularly use the Iceberg Infographic and our '*Open Door'* resource on Neurodevelopmental Conditions as learning tools for social workers
- Challenged a school when a young person was excluded from an OFSTED inspection and refused SEN support for GCSEs. Delivered advocacy for the parent to improve support for additional learning needs. Led a complaint to the Academy Board, the head teacher and SEN staff were replaced, the young person included in exam timetables and achieved 6 GCSEs.
- Promoted information on FASD to the TEWV virtual hub
- Sustained peer support to provide direct, on-going support for 36 individuals and 56 parent carers to gain good quality information, improve problem solving and increased confidence to advocate for their young people.
- Delivered a presentation to the NENC Disability History Month event to raise awareness of FASD as an organic brain injury and life-long neurodiverse disorder. Shared the Iceberg Infographic with 48 attendees.

- The research team completed National Institute of Health Research (NIHR) funded evaluation of My Life Tool in October 2023 and Dr Stephanie Kilinç and Neuro Key coordinated a successful event to launch the results of the evaluation to 78 attendees
- Our contribution to the Parliamentary Committee consultation on safeguarding vulnerable neurodiverse young people accepted by DWP complex case team
- We were contacted by British Land to discuss how to improve their responsibility to neurodivergent people visiting retail shopping parks.
- In March and April 2024, our letters were published in the Daily Mail about the role of unpaid carers, usually family members, the constraints of carers allowance, poor access to health appointments and respite services. The letters page received responses for two months
- In May and June 2024, following the presentations for Disability History Month, Neuro Key was commissioned and delivered presentations to NHS Employers/National Engagement Services (NES) for the North East and North Cumbria (NENC) plus Yorkshire and Humber regions on neuro-disability and neurodiversity.
- We mentored 3 students from Teesside University to research into FASD and investigate the views of NHS and Mental Health professionals.
- Three Volunteers have delivered training sessions to 4 schools to improve understanding of the needs of the neurodivergent community.
- Delivered 3 briefings to the Disability Unit, the growing inequality between neuro-disabled and non-disabled communities significantly reducing life expectancy in the North East
- Highlighted to VCSE regional networks that 90% of young people in fostering and adoption services have FASD but the birth history does not follow the child. Parent carers are specifically denied services until crisis when coping skills are blamed and they become isolated on Mental Health waiting lists.
- In 2025, after we had lobbied for 2 years, the Mental Health, Autism and Learning Disabilities network was renamed Autism and Neurodiversity network. We continue to urge that Autism is also a neurodevelopmental condition and that the ICS networks still exclude FASD.
- Through 2025, we worked with journalists from iNews and Private Eye to highlight poor public sector understanding of the range of neurodivergent conditions and the negative life impact being built into public services to deny opportunities that neuro-typical young people can take for granted.
- Continuously lobbied Voluntary Organisations Network North East (VONNE) networks and representatives of the Integrated Care System (ICS) to recognise FASD and the full range of neurodevelopmental conditions.
- Neuro Key were represented on the strategic development of the Community Mental Health Framework.
- Neuro Key support over 100 benefit applications per year, assist people to understand their symptoms and report to DWP with evidence. With 5 trained volunteers, we apply time through appeal processes if necessary but 90% of applications for PIP are successful up to Mandatory Reconsideration and 10% through HMCT appeal.

Multi-neuro peer support groups since 2015

Geography	**Middlesbrough and surround** **North Yorkshire**	**Richmond, Northallerton, Reeth** **North Yorkshire**	**Hartlepool, Thornaby and surround**
Time	Fortnightly, first and third Tuesday	Bi-monthly	Monthly
Duration	2hours - 6pm to 8pm	2hours - 1pm to 3pm	2hours - last Friday 1pm to 3pm
Who	Anyone living with or caring for neurodivergent adults	Anyone living with or caring for someone with a neurological disability	Anyone living with or caring for someone with chronic pain or neuro comorbidity
Where	Lingfield Ash Hall, Coulby Newham		Thornaby Centre Library
Managed	Neurodiverse adult volunteer	Volunteers	Community Member of Neuro Key
Reporting	Multi-agency /strategic reference	To Neuro Key and local NHS personnel	Multi-agency /strategic reference
Benefit	1. Maximise opportunities to improve parity of health and mental wellbeing 2. Caregiver involvement in decision making, research and education 3. Sharing and learning environment for professional and lived experience collaboration 4. Sustained communication to and from other support networks for peer support and problem-solving for people with ADHD, ASD, Tourette's, FASD, OCD	1. Maximise opportunities to improve parity of health and mental wellbeing in rural settings 2. Service user and carer involvement in decision making, research and education 3. Sharing and learning environment for professional to hear lived experience 4. Sustained communication network for peer support to access expertise or newly diagnosed or rare conditions to reduce isolation in rural community	1. Maximise opportunities to improve parity of health and mental wellbeing 2. Service user and carer involvement in decision making, participants in research + education programme or consultations 3. Sharing and learning environment for professional, service user/carer collaboration 4. Sustained peer support for people to improve self-management skills and inclusion in the wider neuro community
Funding	Benefit-in-kind Free meeting room	Accessible homes	Free meeting room
Contact	T; 07825 031833 E; neurologicallychallenged@hotmail.com	T; 01642 762606 M; 07734 849611	M; 07883 031481 E; dianewilliams1@sky.com



THE NEURODEVELOPMENTAL ICEBERG

Easily distracted

Disorganised

1/8th the tip of developmental delay

Impulsive

Restless

Autism

Attention Deficit Hyperactivity Disorder (ADHD)

Learning disability

Foetal Alcohol Spectrum Disorder (FASD)

Defiance Disorder

Obsessive Compulsive Disorder

Tourette's

Instruction processing

Vulnerable to manipulation, substance abuse or crime

Susceptible to anxiety and depression

Misinterpreted as non-compliant in a system of rewards and punishment

Sensitivity to sensory input

Impaired neuro-transmitters

7/8th of managing daily life hidden below the surface

Planning ahead

Concentration

Decision making

Retention, memory recall

Impact can be mild, moderate or severe, incurable and for life

Cause and consequence thinking

PRESENTATIONS OF NEURODEVELOPMENTAL CONDITIONS

You can change the environment, you cannot change the person

Presentations Explained

Presentation	What this means	Development age of an 18 year old adult
Cause and consequence thinking	Impulsive, emotional, poor comprehension of meaning or impact of behavior on self and others	7 year old
Concentration	Easily distracted and confused under pressure, propensity to obsessions	8 year old
Decision-making	Difficulty understanding or following concept of rules, past experiences/lessons	11 year old
Learning Disability	Levels of presenting behaviors can be mild, moderate or severe	6 - 16 year old
Impaired neuro-transmitters	The neural pathways for thought processing are weak or damaged	6 - 16 year old
Instruction processing	Delayed processing speed to instructions, cannot draw a relationship between words and actions	8 year old
Planning ahead	Unable to reach idea of goal setting or completion of tasks	8 year old
Retention memory recall	Struggles with short and long term memory recollection	6 year old
Sensitivity to sensory input	Extremes of sensations about light, sound, clothing or food	6 year old
Susceptible to anxiety and depression	Reduced emotional maturity, can be violence or trauma informed	11 year old
Misinterpreted as non-compliant in a system of rewards and punishment	Do not understand what is expected or meaning of 'misbehavior', pronounced flight or fight response	7 year old
Vulnerable to manipulation, substance abuse or crime	Low self-esteem, trusting, poor understanding of difference between being liked and being used, poor judgment or common sense	7 year old

NEURO KEY
An Alliance supporting people
with neurological conditions

Newtown Community Resource Centre, Durham Road,
Stockton-On-Tees TS19 0DE
E: admin@neurokey.co.uk | **X:** @NA-TVDNY
T: 01642 641825 | **W:** www.neurokey.co.uk

Registered Charity No:1119043

Iceberg Infographic

During Covid-19 lockdown, Neuro Key's disability advocate developed the Iceberg Infographic as a learning tool for students and NHS professionals in collaboration with Maria Catterick, Foetal Alcohol Spectrum Disorder (FASD) network lead and 2 adoptive parent carers. When lockdown ended, Neuro Key initiated peer support for neurodiverse adults in Middlesbrough. An initial on-line blog by an award-winning peer supporter reached 4,500 England-wide hits from people hoping to attend.

Neuro Key had been supporting an adoptive parent, who had professional and personal experience of neurodevelopmental conditions. Trustees offered a pilot role part-time, to make connections and use lived experience as a learning tool. From forming a collaborative approach with another carer for adopted family members, work began to reduce tenable inequalities against neurodivergent young people.

In December 2023, Neuro Key was approached by MIND Social Prescribing service about FASD. Neuro Key referred MIND to the local FASD expert who was invited to deliver a training session. Neuro Key followed up with a lived experience session for 20 people in March 2024, our lead neurodiverse peer supporter and a parent carer.

- The Iceberg Infographic is used as a learning tool by social workers involved in Tees-wide Fostering and adoption services Virtual School.
- Luke Clements (Cerebra and Professor of Law and Social Justice at Leeds University) described the Iceberg Infographic as *'such a powerful idea and valuable document'*.
- Our contribution of lived experience narratives on FASD recognised by NICE and the Ministry of Justice consultations on neurodiversity in the Youth Justice System.
- Our contribution to the Parliamentary Committee consultation on safeguarding vulnerable neurodiverse young people accepted by DWP complex case team
- Our neurodevelopmental resources are published on the Neurodivergence in Criminal Justice Network (NICJN) out of Bristol University.
- The Iceberg Infographic is used as a learning resource for Alliance Psychology In Stockton on Tees.

Specialist Community Navigator for neurodiverse young people

When lockdown ended, Neuro Key initiated peer support for neurodivergent adults in Middlesbrough. The first on-line blog by our award-winning peer supporter reached 4,500 England-wide hits from people hoping to attend. Responses to feedback and extensive conversations for developing projects 2020-22 proved that neurodivergence Neuro Key held 2 focus groups for parent + kinship carers and engaged with members of the neurodiverse adult peer support group. We launched a survey to consider a whole person approach from the neurodivergent community across the Tees Valley. The community should not be categorised and isolated as 'psychiatric' within the Mental Health domain. In total,120 people designed a unique job role, *Specialist Community Navigator for neurodiverse young people*.

The job description was finalised in early summer 2024 and Neuro Key sought approval from 28 beneficiaries before presenting to 10 Trustees for funding endorsement. The role went live in Redcar in October 2024. We delivered the 1st year funders report across NHS and Public Health agencies in the Tees Valley in October 2025.

Under the Equality Act (2010) and the Mental Health Act (1983), neurodivergent young people are defined as vulnerable and in need of safeguarding. However, these principles coupled with reducing the costs of the public sector has overtaken the day-to-day needs of vulnerable young people. This has driven the blame culture into negative life impact to satisfy increased demand on public services which in turn is causing greater exclusion and fading equality of opportunity. The Equality and Human Rights Commission (EHRC) recommended government strengthens disabled people's right to live independently as part of any community, in line with Article 19 of the UN Commission for Rights of Persons with Disability (CRPD).

Navigating a new Normal - Summit 07.10.25

The Summit was organised to capitalise on 5 years work to bring together professionals, parents, kinship carers and neurodivergent adults to offer time and space for understanding, learning and sharing. In collaboration with stakeholders, we launched the first-year report about the *Specialist Community Navigator for neurodiverse young* people to steer less judgemental strategic policy direction for neurodivergent young people.

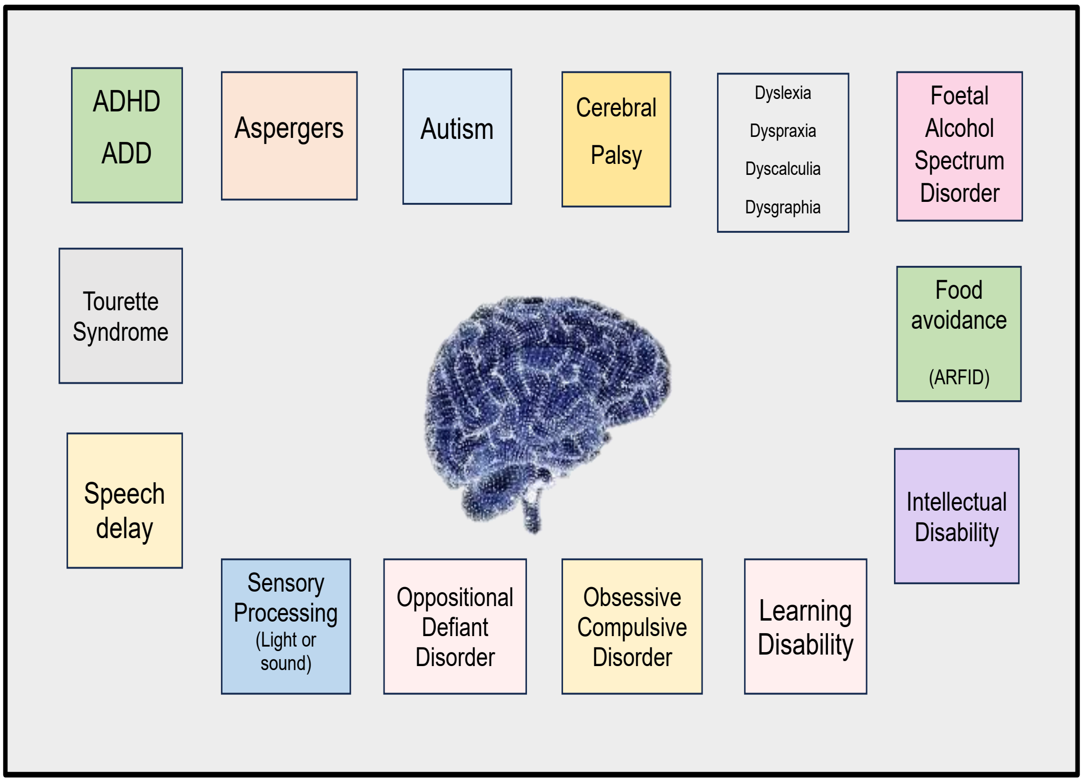
The Summit agenda was designed and achieved, 50% of speakers were neurodivergent and 50% were parent carers. Speakers remained after their session to answer questions and contributed to discussions. A QR code was displayed on screens and printed hard copies for delegates to view a range of questions posed by neurodiverse adults and parent carers.

We enabled discussion about a more inclusive multi-disciplinary, multi-agency approach to service delivery for all neurodivergent young people and their caregivers. Again, we achieved our usual target, 50% of delegates were Health and Social Care professionals and 50% neurodivergent adults and parents/kinship carers of neurodivergent young people.

It is vital to reduce the current negative life impact, health inequality and isolation, the Summit was to explore how delegates wanted this to be achieved. As we approach 2026 the reality is,

- The Tees-wide 'Professional's Consultation Hotline' does not include FASD, Tourette's or co-morbidities, dyslexia, dyscalculia, dyspraxia, dysgraphia, eating disorders such as food avoidance (ARFID) or sensitivity to light or sound.

- In the House of Commons Library, the ‘PIP by Constituency’ documents outline anxiety, depression, Autism and learning disabilities as ‘psychiatric disorders.’ This label contributes to the negative life impact through waiting lists and poor professional knowledge, stigma and systemic exclusion of 75% of neurodevelopmental conditions.
- There are no NHS diagnostic services for FASD in the Tees Valley.
- Birth History does not follow an adopted or fostered child.
- The reduction of the Adoption and Special Guardianship Support Fund (ASGSF) has disproportionately impacted FASD families by removing the ability to secure a private-funded diagnosis.
- The ASGSF therapy fund has been redefined as a general fund which further inhibits access to both diagnostic and therapeutic interventions.
- The Infographic was launched at the summit to define neurodivergence.

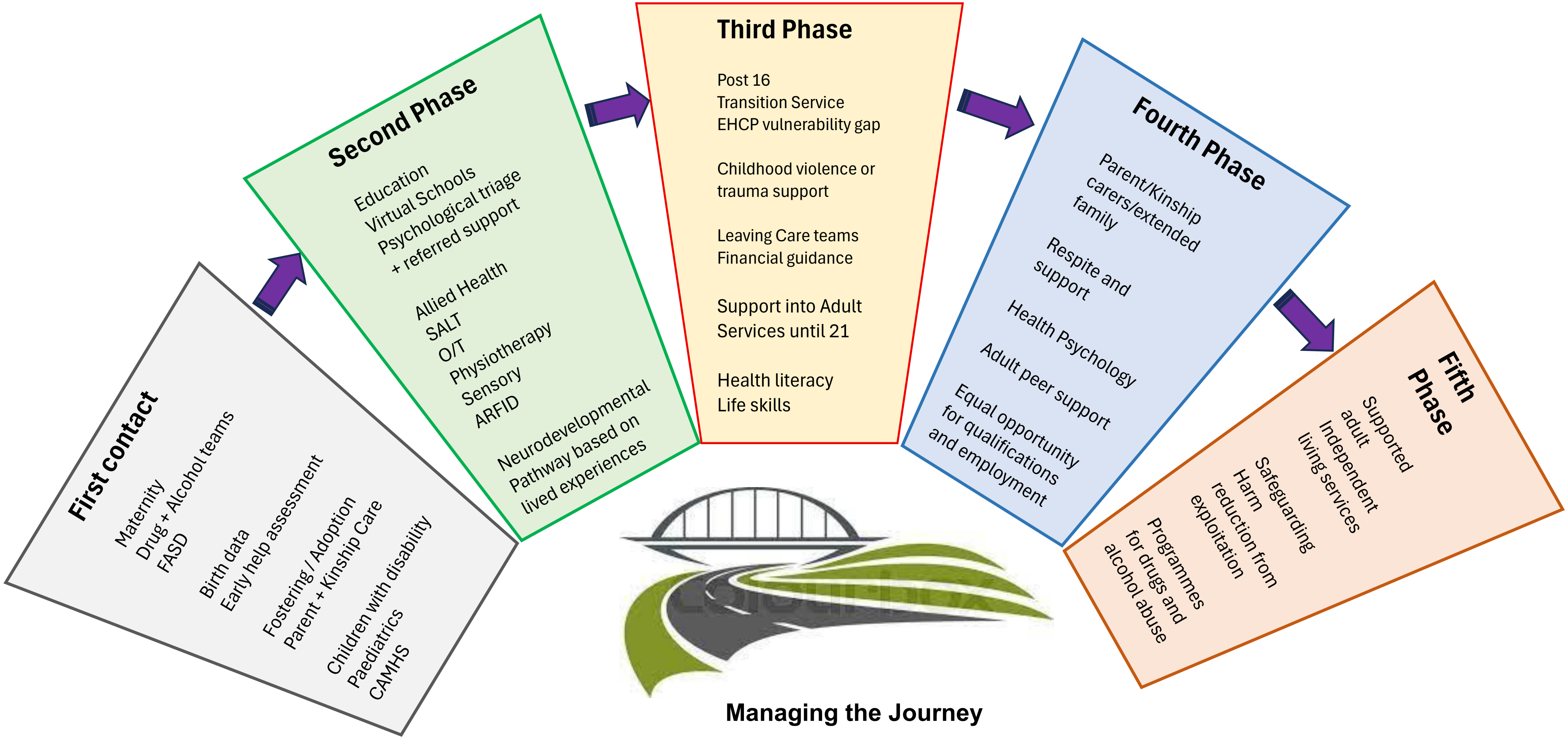


Our main sources of income for this work have relied largely on donors, donations and grants. Funding arrangements for many Charities in 2025 has become extremely difficult with funders universally reporting huge over-subscription of funding applications for limited funds. Neuro Key have not had statutory sector funding since 2014 and whilst this offers some independence, we deliver benefit for increasing demand with constrained funds to cover some of the gaps in the public sector knowledge base. With a prevalence rate of 1% of the population with Autism and 2% with FASD, the key challenge for neurodivergent people is recognition of the co-occurring conditions requiring access to specialist expertise and support.

NEURO KEY

An Alliance supporting people
with neurological conditions

Following our Resilience project for TEWV in 2021-22, we developed a deep understanding of how fragmented and inaccessible services were for a range of families managing neurodivergence. This infographic was designed to offer potential for a whole system, inclusive, strength-based approach for neurodivergent young people in the future.



First contact

Maternity
Drug + Alcohol teams
FASD

Birth data
Early help assessment

Fostering / Adoption
Parent + Kinship Care

Children with disability
Paediatrics
CAMHS

Second Phase

Education
Virtual Schools
Psychological triage
+ referred support

Allied Health
SALT
O/T
Physiotherapy
Sensory
ARFID

Neurodevelopmental
Pathway based on
lived experiences

Third Phase

Post 16
Transition Service
EHCP vulnerability gap

Childhood violence or
trauma support

Leaving Care teams
Financial guidance

Support into Adult
Services until 21

Health literacy
Life skills

Fourth Phase

Parent/Kinship
carers/extended
family

Respite and
support

Health Psychology

Adult peer support

Equal opportunity
for qualifications
and employment

Fifth Phase

Supported
adult
Independent
living services

Safeguarding
Harm
reduction from
exploitation

Programmes
for drugs and
alcohol abuse

Managing the Journey

We advocate for a brain health model to build knowledge, recognise and understand the full range of neurodivergence

Inter-agency Strategic Policy direction and Leadership

- Integrate two-way flow of information to build a bridge for each phase
- Curate professional tools and resources with a handover process to sustain knowledge
- Identify each agency’s learning needs to create the care pathway
- Diagnostic and assessment model for Autism not appropriate for FASD, an organic brain injury
- Policy restrictions prevent FASD being recognised in Disability Teams
- Implement education and training for a new generation of health psychology professionals

Urgent

Recognise 3rd sector expertise

- Involvement in redeveloping the system
- Liaison with Fostering and adoption services
- Deliver skilled advocacy, advice and guidance
- Right time and place support for parent and kinship carers
- Include collation of real-time data for Public Health
- Movement of information to reduce myths and assumptions
- Inclusive, non-judgemental peer and social networks
- Reduce judgemental harm and tackle disability abuse

Create a Baseline

Stepped Model of care based on ‘life with’, not ‘sorry you don’t fit criteria’.

- Reduce isolation of full range of neurodivergence
- Improve negative life impact of school exclusions and life chances neuro-typical peers can take for granted
- Reduce labelling to actively prevent inequality of opportunity for education
- Reduce culture of blame against fostering and adopting parents
- Deliver annual health checks to improve knowledge about impact of health inequalities
- Address neuro-disability not recognised in the Education Health Care Plan (EHCP)

Output

Our core values explained

Passionate about our social purpose

Positive and asset-based

Collaborative sharing and learning

Transparent, Inclusive and accessible

Ethical, caring and compassionate

Outcome-led not target driven

Passionate about our social purpose	Positive and asset-based	Collaborative sharing and learning	Transparent, inclusive and accessible	Ethical, caring and compassionate	Outcome-led not target driven
*We are innovative, driven and committed *We sustain a track record of impact and improvement *Work in partnership across a range of agencies to contribute to a seamless care pathway *Enable people with neurological disability or neurodivergence to Participate in a 360° cycle of communication *Broker common purpose for all neurological conditions, injury, impairments, disability and neurodiversity	*People with lived experience are an asset not a burden *Increase community membership and engagement *Encourage a culture of mutual exchange and challenge *Reduce barriers to engagement, both perceived and real *Promote lived experiences as drivers for change	*Work in partnership with Health and Social Care to improve outcomes *Improve understanding of life with a disability *Contribute lived experiences for decision-making, service priorities and delivery *Contribute to the knowledge base in education and research *Promote self-management of conditions to reduce the decline into early disability	*Broker co-production between professionals and people living with neuro-disability, their families and caregivers *Foster a work environment that responds, supports and sustains a high level of focus on customer care *Willingly participate in scrutiny and review through trust and transparency	*Deliver honesty, openness and respect *Promote a person’s right to sensitivity, courtesy and dignity *Protect and safeguard people from risk and harm *Promote personalisation to support control and choice *Inclusive model fo delivery that leaves no-one behind	*Promote problem-solving with up-to-date information and connection *Deliver efficiency with prudent use of resources *Strive for excellence with agreed standards of practice for outcomes and impact *Proactively seek evidence, good practice and contribute to feedback and review

From September 2019 to 2024, Neuro Key were core members of the NE Regional Stakeholder Network to improve awareness of life with a disability. Briefings were developed for onward consideration by the Disability Unit and Cabinet Office on;

a) Blue Badge accessibility- 2.26million qualify but only 42% receive a Blue Badge (www.gov.uk). Neuro Key worked with a journalist to gather data from Freedom of Information requests across the NE about Borough Councils compliance with Blue Badges and Blue Badge parking spaces. Whilst not mandated, Councils should offer 6% of their overall parking facilities to Blue Badges. The worst Borough was Middlesbrough at 2.3% and the best Borough was Redcar at over 8%
b) Equity of access to transport, trains or buses for disabled people to get to work in England. We raised the issue of buses offering seats on a first-come-first-served basis which gave preference to baby buggy's not wheelchairs or walkers.
c) A pivotal issue that has risen since Covid lockdown is the front-line use of mental health medications regardless of a person's metabolic suitability. Neuro Key drafted a briefing on Tardive Dyskinesia, a neurological movement disorder caused by toxicity of medications given for mental health diagnoses such as chronic depression or schizophrenia over a long period of time. The briefing explained the impact of harm caused by poor knowledge for patients and caregivers
d) Growing inequality between disabled and non-disabled communities influencing a reduction of life expectancy in the North East of England. We highlighted the prevalence of suicide amongst neurodivergent males plus the rates of neurodivergent adults in the Youth Justice System.
e) Following a death of a beneficiary in 2022, we lobbied to improve DWP recognition of medical conditions to reduce the level of perceived ignorance and harassment against PIP applicants.

Taking participatory research forward

With Dr Stephanie Kilinç, we have sustained a biopsychosocial approach to reduce the concentration on medicalised labels and offer new thinking to the management of long-term conditions (LTC) and disability. Our collaborative model improves self-efficacy, reduces negative feelings of failure due to an LTC and disability, builds resilience to manage, not simply cope to survive but actively control the impact of the diagnosis to thrive.

Informed consent is one of the founding principles of research ethics. People engage with research projects voluntarily and should be given full information about what it means for them to take part. That consent is freely given before they engage with the researchers, there should be a reciprocity or equal benefit through the work.

We deliver an innovative opportunity for people to volunteer their lived experience as a learning resource. We build a strong rapport with beneficiaries to sustain a robust pan-neuro voice, inclusive of carers to bolster the body of knowledge.

The Peer Researcher's Back Pack

Since 2014, we have sustained a space between Teesside University and Neuro Key to empower people living with a range of long-term conditions (LTCs) or neuro-disabilities as equal partners in research. We harness creativity, refresh skills, build confidence and improve participants self-care. Our participatory research programme has uncovered a new language, less academic and medicalised, a more listening, person-centred approach to enable participants develop research skills, lead projects and become recognised co-authors.

Through our co-authored self-management programme, My Life Tool defined a reflective process for people to find meaning and purpose in their health journey and not be defined or isolated by the label of their diagnosis. The Tool has been adapted to offer My Creative Life and Long-Covid versions. My Life Tool improved our participants belief that through reflection, they can achieve specific goals, choices or decisions to build resilience and withstand the challenges of their chronic health conditions. In addition, we have fostered community-led solutions within organisations such as the Mental Health Trust, MIND, Darlington Action for Disability (DAD). We enable peer support as a learning and sharing environment for people living with a wide range of LTCs.

We developed the rationale for the My Life Tool project, recruiting participants from across the Tees region. We designed a training programme whereby participants could opt to be trained as peer mentors and assist participants to use My Life Tool for a period of time. We evaluated the efficiency of the tool to improve their well-being and coping skills. The evidence gained from a literature review highlighted that models of peer research were largely compiled by and for, academic researchers.

In 2024, the research team secured funding to analyse the data and evidence surrounding peer-led research. We recruited participants from our community network to steer the production of a toolkit as a learning resource for people to strengthen equality of opportunity in research. We aimed to develop the notion that peer research participants should be equals in research and credited for their contribution.

Dr Stephanie Kilinç and Jo Cole, Neuro Key had no pre-conceived idea of what the format of the toolkit could be. The team devoted time to get to know each other, develop their thinking, consider the terminology around *health journey*, *creativity in health*, the challenges of *self-management* and *isolation-by-diagnosis*. The conclusion enhanced the idea of a hike where people compile a kit to stay safe and build knowledge for the task, with a compass, multi-tool, supplies or map. The project was named the Peer Researcher Back Pack. The tool included journey mapping, travel updates and skill badges similar to scouting/guiding achievements to represent qualities that peer researchers could develop as partners in research. In developing their skills, peer researchers build an equal partnership with academics to embed the value of lived experience into the body of knowledge and drive social change.

Publications to improve professional knowledge

- Since 2015, we have published 'Unlocking minds and opening doors' learning resources based on narratives of lived experiences with participants contributing learning outcomes; Dyslexia, ABI, Neurodevelopmental conditions, including the Iceberg Infographic, FASD, Friedrichs Ataxia, Diverse carers, Dystonia - narratives of Tardive Dyskinesia to be published in 2026. www.neurokey.co.uk

- Improved recognition and inclusion of parent, elderly or kinship carers for any neurological condition in the 2021-26 South Tees Carers Strategy - https://wecareyoucare.info/professionals/south-tees-carers-forum

- Published to Disability and Rehabilitation Journal
  'Finding Meaning and Purpose: A Framework for the self-management of Neurological Conditions' (Kilinc, Erdem, Healey and Cole) - May 2021

- Co-authored My Life Tool - http://www.mylifetool.co.uk/

- Shepherdson., N, Jervis, V., Trent, M., 2024 - *An Autistic Anthology: Neuro-Narratives of Mental Health Professionals:* KDP – 25% of sales to Neuro Key

- Recognising people with lived experience credited in research https://arc-nenc.nihr.ac.uk/resources/the-peer-researchers-backpack/ - January 2025

- Practical Health Psychology **-** Translating research to practice, one blog post at a time August 2025, published in 25 languages.

  https://practicalhealthpsychology.com/2025/08/mylifetool-a-person-centred-holistic-approach-to-the-self-management-of-long-term-conditions/

  https://www.linkedin.com/posts/dr-laura-dennison_mylifetool-a-person-centred-holistic-approach-activity-7368369672703975424-

- Excellence in Health Creation Alliance Awards - October 2025:

  "Best health creating grassroots approach to reducing the impact of long-term conditions"
  ✨ Runner up - My Life Tool - partners Teesside University and Neuro Key

- Co-producing Research with Community Members: Case Studies from Health, Social Care and Education - Professor Dorothy Newbury-Birch
  CHAPTER 13: Embedding authenticity in peer research Joyce J, Fitzgerald, Chalkley R, Williams G, Wilson J, Cole J, Kilinc S - to be published 2026

The Future

In 2015, we reported that a robust, community-based support framework is essential to access good information, peer support, advocacy and sometimes, just a listening ear. These are important factors for people to build resilience and problem-solving skills to overcome systemic barriers. There is no doubt, Health and Social Care systems should take a more inclusive approach for prevention of crisis, self-management and coproduction of care pathways closer to home.

Our explicit, person-centred approach is not target driven but committed to improving outcomes by directing our extensive knowledge of neurological need across all sectors of the region. We are non-judgemental, trustworthy, flexible and reliable in our motive to effect more lasting service transformation for the neurological community.

As we develop our strategy for the next decade, we will work to advocate for a more joined up, seamless journey for people diagnosed with any neurological condition. Our model will echo our former Chairman with an exception, ‘life with …..’ *and not* ‘sorry you don’t fit our criteria’.

Information resources

- Aiton N (2021) Neglect of foetal alcohol spectrum disorder must end. BMJ 375, doi:10.1136/bmj.n2969, pmid:34872904. n2969.
- American Psychiatric Association. (2022). *Autism Spectrum Disorder.* In Diagnostic and Statistical Manual of Mental Disorders (5th ed.) https://doi.org/10.1176/appi.books.9780890425787
- Arnold, S. R., Huang, Y., Hwang, Y. I., Richdale, A. L., Trollor, J. N., & Lawson, L. P. (2020). “The Single Most Important Thing that has Happened to Me in My Life”: Development of the Impact of Diagnosis Scale. *Autism in Adulthood*, 2 (1), 34-41. https://doi.org/10.1177/10731911231196486
- Betancourt, J. R., Green, A. R., Carrillo, J. E., & Ananeh-Firempong, O., 2nd (2003). Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health reports (Washington, D.C.: 1974)*,*118*(4), 293–302. https://doi.org/10.1093/phr/118.4.293
- Capp, S., De Burca, A., Aydin, Ü., Agnew-Blais, J., Lautarescu, A., Ronald, A., Happé, F. and McLoughlin, G. (2024). Depression and anxiety are increased in autism and ADHD
- Darzi - Independent Investigation of the National Health Service in England
- Department of Health and Social Care (2021) Guidance: fetal alcohol spectrum disorder: health needs assessment. accessed. https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment/fetal-alcohol-spectrum-disorder-health-needs-assessment

- Department for Work and Pensions - young people with mental health conditions are nearly five times more likely to be economically inactive - https://www.gov.uk/government/publications/keep-britain-working-review-discovery
- Evans, S., Pringle, H., Sandner, Z., & Hayley, A. (2025). Exploring parents' experiences of interprofessional collaboration among health professionals in the assessment and support of autistic children, *Journal of interprofessional care*, 1–9. https://doi.org/10.1080/13561820.2025.2462131
- Fish, Rebecca et al. "It's about Equality!" Disability Advocacy in the UK - (2025)
- * FOI ICB 25 243 Response Letter
- Khalil, A., Yatcilla, J., Christie, N., & Zhou, X. (2025). A Systematic Review of Help-Seeking Barriers for Racial-Ethnic Minority Caregivers Accessing Autism Diagnostic and Intervention Services. *Journal of racial and ethnic health disparities*, 10.1007/s40615-025-02555-x.
- * https://www.neural.org.uk/publication/invisible-patients/
- NHS England (2025) Fit for the future: 10-year health plan for England (NHS England), accessed. https://www.england.nhs.uk/long-term-plan/
- NICE - autism spectrum disorder in under 19s: support and management (Clinical Guideline CG170 - https://www.nice.org.uk/guidance/cg170
- Papoudi, D., Jørgensen, C.R., Guldberg, K.et al (2021). Perceptions, Experiences and Needs of Parents of Culturally and Linguistically Diverse Children with Autism: *Review Journal of Autism and Developmental Disorders, 8,* 436–452. https://doi.org/10.1007/s40489-020-00210-1
- Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: Mothers, disabled children and disability studies in *Disability & Society, 23*(3), 199-210.https:// doi.org/ 10.1080/ 09687590801953937
- Shepherdson., N, Jervis, V., Trent, M., 2024 - An Autistic Anthology: Neuro-Narratives of Mental Health Professionals: KDP
- World Health Organization. (2019). *6A02* Autism Spectrum Disorder International Statistical Classification of Diseases and Related Health Problems (11th ed.) https://icd.who.int/browse/2024-01/mms/en#437815624
- World Health Organisation - Global status report on neurology - 2025 https://www.who.int/publications/i/item/9789240116139
- Zuckerman, K. E., Mattox, K. M., Sinche, B. K., Blaschke, G. S., & Bethell, C. (2014). Racial, ethnic, and language disparities in early childhood

Neuro Key
December 2025