

NEURO KEY

An Alliance supporting people
with neurological conditions



TEWV RESILIENCE FUND

Project report March 2022



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Foreword

The World Health Organisation (WHO, 2012) reported that neurological conditions were the leading cause of disability in the UK equating to 1/3 the burden of all diseases and representing more than heart disease, cancer and diabetes combined. The WHO considered neurological disorders were seriously underestimated, largely defined by mortality rates, not disability rates. A Public Health England (PHE) 2018 report proved that life expectancy for people with a neurological disability has been decreasing since 2001. Over the past 20 years, the burden of neurological disorders has increased substantially without the necessary service awareness, capacity and infrastructure needed to manage increasing demand. There has been no quantifiable improvement to services for neurological patient outcomes since 2005.

We improve professional understanding of the common threads between neurodevelopmental conditions and how people manage complex socioeconomic roles along with the long-term caregiving role through our education programme at Teesside University, through our 'Open Door' series of learning resources and through a range of local, regional and national networks and forums.

With just 11% of the neuro-client group having a care plan (Neurological Alliance 2016) there is increasing recognition of the burden on caregivers but reducing risk of crisis and improving outcomes cannot rely on the actions of health and allied practitioners alone.

By enabling neuro-diverse people and their caregivers to be part of strategic communication cycles, we can directly improve the self-awareness of Education, NHS, Social Care and Mental Health professionals to improve the body of knowledge and comprehend the reality of the frontal lobe paradox and the needs of a person managing any neuro-diverse condition.

Our Proposal and Aims

Proposal

1. Construct a platform for regular on-line, telephone or face-to-face engagement with families to report on their lived experience of managing the challenges of neurodevelopmental conditions during the pandemic lockdown and in the aftermath.
2. We will facilitate outreach at Coulby Newham and St Mary's Centre for safe and trustworthy access to expertise, knowledge and advocacy for people with neurodevelopmental conditions to include FASD, connecting people to networks, peer support and sources of information to problem-share, reduce isolation and fear.

Joanne Cole is a qualified counsellor with a BSc in Critical Practice in Health and Social Care, Maria has an MA in Applied Social Science - Managing Community Practice with a dissertation on FASD in Adults. Our volunteers have undertaken the PHE module on mental health to sustain their own emotional wellbeing when delivering peer support. We also have a volunteer with neurodevelopmental co-morbidities who recently won a Teesside Hero Award from the Middlesbrough based Teesside Charity for his peer support and work at Teesside University.

3. We will deliver a pilot peer mentorship programme for young people with neurodevelopmental conditions in Middlesbrough schools who are at risk of exclusion due to their condition presentations not being understood.
4. As core members of a range of network and Forums, we will be promoting access to parent carer forums or encouraging sign-up to the Middlesbrough disability register.

Aims

- Define the need for specific attention to improvements in care for young adults aged 18–25 years living with a neurodevelopmental condition.
- Reduce the negative life impact on young people with FASD and the impact on parent carers.
- Reduce the fear and isolation imposed by the lack of services and impact of the coronavirus pandemic caused by working constraints and fragmented communication chains.

Proposed Outputs

1. Construct a platform for regular on-line, telephone or face-to-face engagement with families to report on their lived experience of managing the challenges of neurodevelopmental conditions during the pandemic lockdown and in the aftermath.
 2. Facilitate outreach at Coulby Newham and St Mary's Centre for safe and trustworthy access to expertise, knowledge and advocacy for people with neurodevelopmental conditions to include FASD, connecting people to networks, peer support and sources of information to problem-share, reduce isolation and fear.
 3. Deliver a pilot peer mentorship programme for young people with neurodevelopmental conditions in Middlesbrough schools who are at risk of exclusion due to their condition presentations not being understood.
 4. The TVDNY Neurological Alliance publish narratives of lived experience as learning tools on FASD (2017) and Neurodevelopmental Conditions (2021) and Neurodevelopmental Iceberg graphic (2021) as a training handout - www.na-tvdny.org.uk. Our proposal will include distribution of 100 hard copies of the resources to a range of agencies in Middlesbrough to improve access to expertise, share knowledge and improve outcomes for the client group.
- We delivered a focus group for parent / kinship carers of people with neurodevelopmental conditions including 4 parent carers supporting young people with anxiety, dyspraxia, personality disorder, autism, FASD, ADHD, Tourette's, learning disability, sensory disorder and Fragile X ataxia, 2 grandparent carers supporting FASD, ADHD, and personality disorder and a carer living with Tourette's syndrome, ADHD, and sensory disorder. 100% of attendees wanted to be involved in consultations in the future.
 - We distributed 50 copies of the Neuro Key Iceberg poster and 32 copies of our Open Door Neurodevelopmental resource before December 2021.
 - FASD network lead, Maria Catterick hosted an information table at the Education Conference at the Riverside Stadium on February 11th 2022 and distributed 120 FASD resources, 30 Neurodevelopmental Conditions resources, 40 Peer group flyers and 50 copies of the Iceberg posters.
 - Following discussions at peer group meetings, 3 parents signed up to the Middlesbrough Disability Register and the Northern Power Grid Vulnerability register.
 - We attended 3 Parent Carer Forum and 3 Criminal Justice System meetings to raise awareness of incidence of FASD in Middlesbrough, gave a 'neuro-developmental conditions' presentation to the ICS Mental Health Network and began communications with Roseberry Community Consortium which covers Tees Valley Dyspraxia support.
 - We are liaising with a student and the Dyslexia group to form a new Open Door resource for our neurodevelopmental portfolio of narratives.

Project Methodology

- We worked collaboratively through website contact forms, telephone, word of mouth, Parent carer forums, published flyers and social media plus network connections, to create a platform for families to report on lived experiences.

Proposed Outcomes

1. Improve access to safe, experienced peer support for at least 20 adults with a range of neurodevelopmental conditions.
2. Enhance engagement with 10 FASD families to build trusting relationships, improve confidence, problem-solve and be supported to manage regular crisis episodes.
3. Mentor 10 young people with neurodevelopmental conditions in Middlesbrough schools who are at risk of exclusion due to poor understanding of presentations.

Delivered outcomes

- ✓ We have improved attendance at the monthly peer support group meetings for adults with a range of neurodevelopmental conditions at Langdon Square Community Centre, Coulby Newham by 30%
- ✓ Supported 18 people with age ranges 25 - 54years, informed 2 Middlesbrough nurses and 4 parent carers
- ✓ We have engaged with 10 Middlesbrough FASD families
- ✓ A schools education programme has been defined and 2 Middlesbrough schools and the Catholic Academy Trust have engaged to have awareness raising training across their portfolio of 20 schools in the Tees Valley. The schools programme has been hampered by the continued restrictions caused by the Omicron variant
- ✓ 5 young people have been individually mentored to resolve exclusion and abuse issues at school
- ✓ Delivered face-to-face support for 4 adults with anxiety and poor self-esteem

Reported feedback

Navigation of the current 'system' by parent carers exposes;

- Poor listening skills in the public sector
- Diagnostic and assessment model for autism not appropriate for FASD
- Lack of annual health checks create health inequalities
- Education/training much needed for a new generation of health professionals
- Poor working collaboration between relevant services
- Poor recognition of life-long hidden disability and support for caregivers
- Service delivery based on the myth that FASD only occurs from mothers with alcohol dependency encouraging a blame culture which inhibits progress
- Poor practitioner understanding of the impact and disruption of sensory presentations in the school years
- Constant fear and anxiety for family carers

Barriers for Parents

- Lack of understanding of the impact of children moving through school years without skilled support
- Homogenisation of service frameworks harms children with learning deficits
- Neuro-disability is not recognised in the Education Health Care Plan
- Parents must choose between a cognitive or a behaviour assessment
- The assumptions and myths that blame, stigmatize and isolate parents
- Practitioner belief that children grow out of neurodevelopmental conditions
- Parents know the triggers, symptoms and presentations but are ignored
- Schools programmes are fragmented with poor consistency to SENCo services. Lack of skill inhibiting cooperation and mediation with physical assaults against children with neurodevelopmental conditions common and unresolved
- Children being failed due to no FASD diagnostic capacity in Middlesbrough
- Families are not eligible for children with FASD to engage with Disability Teams due to policy restrictions that prioritises Learning disability and Autism, yet this is the gateway to personal budgets and care support
- If FASD children have a rare Education and Health Care Plan (EHCP) should protect them to 25 years unless they leave education which many do. The EHCP ends on departure from education
- No transition services from school to adulthood with poor understanding in tertiary and further education systems

Case from a peer support meeting;

A Middlesbrough adult denied diagnosis and support from CAHMS and moved into adult life struggling and feeling a failure.

Neuro Key one-to-one support identified lots of ADHD traits and because of masking, denial and just trying to cope, they suffered from acute anxiety and stress.

They recognised how isolated this makes people as they feel they don't fit in anywhere, are not encouraged to have aspirations or receive adequate support to gain qualifications. The labelling process seems to deny an education and label them useless.

Middlesbrough resident blog; Hiding neurodiversity in plain sight, a lifetime of masking suppressing and acting;

<https://neurologically-challenged.co.uk/hiding-neurodiversity-in-plain-sight-a-lifetime-of-masking-suppressing-and-acting/>

Moving Forward Post-pandemic

1. The Children's Society will include FASD on the Prevention Programme and work collaboratively with the FASD Network to address exploitation of neuro-diverse vulnerable young people
2. The Ministry of Justice confirmed inclusion of FASD in neuro-diverse conditions for a review and development of strategic and inmate services
3. Three Neuro Key publications, narratives of lived experience on Neurodevelopmental Conditions, FASD and the Iceberg graphic on neurodevelopmental presentations plus a Middlesbrough resident case study about the criminal justice system have been accepted for the Resource Collection for the Neurodivergence in Criminal Justice Network (NICJN) out of Bristol University, www.uwe.ac.uk/research/centres-and-groups/global-crime-justice-security/neurodivergence-in-criminal-justice
4. Worked collaboratively with Mark Bradley, TEWV Consultant Clinical Psychologist - inclusion of FASD on the Conference Agenda - April 26th 2022
5. Sustained collaboration with Parents for Change to improve awareness, communications, advocacy and support
6. Delivered awareness of neuro-diverse presentations at seminars to 103 psychology students at Teesside University
7. Participated in 5 roundtable discussions with the National FASD organisation
8. As a member of the National Power Grid (NPG) Expert Panel for vulnerable people to improve access to support during power cuts/outages, Neuro Key distributed 50 booklets to promote the Vulnerability Register.
9. Featured - <https://wecareyoucare.info/articles/family-support-service-drop-ins>
10. The Middlesbrough peer group featured on <http://aadhd-ne-uk.weebly.com/>
11. Promotion of Middlesbrough peer support reached 4,500 hits on social media
12. Roseberry Park has initiated contact to explore a referral process to access peer support for people with neurodevelopmental conditions leaving the service

Two questions have arisen during this project that need answering.

1. Why are NHS diagnostic services not available in the Tees Valley?

It is not appropriate for parents or grandparents (without any funding support) to have to pay up to £2,000 to secure a diagnosis of FASD when they are a caregiver of a vulnerable person.

2. Who should be accountable?

The developing Integrated Care Systems refer to innovation and coproduction to reduce 'historic' commissioning but for the FASD client group, there are no adult services and the new NICE guidance is for children only.

Neuro-diversity is for life.

Recommendations

1.

From feedback with families, they repeatedly report that the current commissioned offer of a family support service is not what they need. Advocacy is specifically excluded.

What is urgent is skilled support in meetings with education, CAMHS and Mental Health. Practitioners not only must have an understanding of FASD, but also the broader range of neurodevelopmental conditions.

Services must be appropriate to need, reduce the blame on poor parenting, school exclusions or not meet criteria for social or respite care. One of the core elements of parent complaint is the chronic lack of pragmatic support to reach a diagnosis.

They do not need 'drop ins and chats'. Parents need a care pathway to follow.

Create an FASD Champions Network led by a senior safeguarding or public health professional.

A Tees Valley wide FASD strategy and good practice guide could be developed to underpin the NICE Fetal alcohol spectrum disorder guidelines, published on March 16th 2022.

There should be a nominated member from across Tees Valley services:

- health promotion
- alcohol harm reduction teams
- education/virtual schools
- maternity
- paediatricians
- psychology/CAMHS/neurodevelopmental pathway
- fostering/adoption services
- early help/edge of care teams
- safeguarding/exploitation/police
- adult services
- leaving care teams
- voluntary sector including lived experience representatives

2.

Alcohol related deaths have risen sharply during the Covid pandemic, (The Liver Trust and BMJ - <https://www.bmj.com>) but there is no data about how many babies have been born with FASD during the time.

Initiate an investigation into birth data from 2020 and establish a register to gauge needs for the future. This must create new thinking, not sustain the current culture of blaming the parent, but define mental health/ disability service capacity needs in the future.

Recommendations

3.

The skill shortage was a recurring theme in discussions with families. The gap between compulsory education ending at 18 years leaves young people with complex needs badly adrift from systems that should be protecting their vulnerability plus, directing vital information, advocacy and supporting parents.

Review the service and skill infrastructure gap between compulsory education to 18 years and the expected service for young people with neuro-developmental conditions that should be delivered to 25 years. There must be improvements to communication chains to protect vulnerability and reduce the negative life impact which leads to 38% of young people with neurodevelopmental conditions being criminalised in the Youth Justice System.

4.

FASD young adults rarely have a Learning disability (LD), thus do not meet LD team thresholds and are rejected. Those who do have an LD are only offered help for a crisis.

A self-fulfilling prediction is the bedrock of current service delivery leading to perpetual crisis management without thought to the negative life impact on parents or the young person. Service design and delivery should be calibrated on self-management, confidence building and access to opportunities for aspiration such as developing skill or employment opportunities.

5.

FASD children have developmental delays and are not ready to access 'adult' services or sit with people of 18+ in groups. Health services may transfer children to adult services at 16 years but fostering social workers phase children to adult social workers at aged 15 and Paediatricians often sign them off paediatric services at 16.

Currently, public systems are siloes. Young people and their parents are pushed from one service to another with long waiting times but no actual service delivery, consistent messages, problem-solving or accountability for their vulnerable situation.

Close the vulnerability gap in the 16-18 year phase to actively prevent neuro-diverse teenagers falling through, feeling angry and failed to become easy prey for those who manipulate vulnerable young people.

There should be a formal, multi-agency approach to recognise that 70% of FASD children are within the Fostering and Adoption services and a collaborate approach is vital to streamline the process to enable parents to access support and reduce the blame culture.

FASD children are not eligible for Mental Health services as a standard offer. Mental Health view FASD as a disability not an organic brain injury with mental health co-morbidities. Access to typical Mental Health services affecting the wider population ie for depression or anxiety is an inappropriate model based on recovery. FASD training is urgently needed to adapt or adjust services to the specifics of FASD co-morbidities which are life-long.

Recommendations

6.

www.healthline.com defines a new study that autistic people have more than 3-fold higher rates of suicide than the general population. The average life expectancy for those with FASD is 34 and for Tourette's/chronic tic disorders the suicide rate is over 4 times the average population.

The Disability Adjusted Life Years (DALY) metric needs a framework to include neurodevelopmental conditions and prevention of early death should be underpinning all Joint Strategic Needs Assessments for Health and Well-being Boards and the Community Mental Health framework.

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7.

Families on the ASD pathway for comorbid diagnosis are sitting waiting for months for an ASD appointment with CAMHS. This inhibits progress and due consideration at school and increases the negative life impact. One grandparent reported being sent on 6 parenting classes due to a perception of poor parenting.

Conduct a strategic review into CAMHS services to improve access, improve the relationship in school and reduce parent blaming and multiple referrals to parenting classes.

Create a database to enable transfer to adult school leaving services.

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Tees Valley Durham and North
Yorkshire Neurological Alliance
Registered Charity No: 1119043

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