



**ENOUGH: THE INEXCUSABLE TREATMENT
OF BRAIN INJURED CHILDREN AND
YOUNG PEOPLE IN THE TEES VALLEY**

FINAL REPORT

OCTOBER 2017

1.0 EXECUTIVE SUMMARY

- 1.1** MATRIX Neurological is an innovative children’s charity based in Middlesbrough, established to provide practical help and support to children, young people and their families who are living with the effects of an acquired brain injury (ABI). The founder of Matrix created the organisation because of first-hand experience of child brain injury. In 2010 her son sustained a severe brain injury. We were established to try to bring about significant changes for brain injured children and young people.
- 1.2** Our mission is: *“to work to remove health inequalities for children & young people affected by acquired brain injury; and provide effective support to their families that makes a real difference”*.
- 1.3** Before Matrix Neurological was established as a registered charity, much research and consultation was undertaken to justify its creation. Professionals tell us that lots of research has been completed pertaining to paediatric acquired brain injury; but nobody does anything with it. Matrix was founded as a registered charity to take those findings and recommendations and find effective solutions to start to deliver improved outcomes for children and families. We do not want to point the finger of blame at others; only to raise awareness and become part of the solution. However, the scale of the problem regarding childhood acquired brain injury is significant and the scale of need should not be underestimated.
- 1.4** In July 2016 we were awarded £38,000 to commence our Family Support Project. The outcomes as a result of this project were anticipated to be:
- Improved quality of life for people with long term conditions by helping families to learn and understand about their child’s long-term condition
 - Focus on groups in need; i.e. Patients with long term conditions by helping parents to support and manage their child’s health problem and enabling them to live in their own home
 - Supporting parent carers
- 1.5** We also envisaged this project would support and enhance existing NHS service provision and help to provide better outcomes for children and young people living with an acquired brain injury, by providing for the unmet needs of their parents and carers to improve or reduce the development of serious mental health issues arising from their caring responsibilities.
- 1.6** As a charity one of the our big ambitions is to make the Tees Valley the best-informed region in the country about acquired brain injury in children and young people through awareness raising, so that we can start to address the significant inequalities that brain injured children experience every day. During the delivery of this project we have learned so much that needs to change regarding brain injured children and young people; but this is a huge task and will take years to complete. However, through this project we are now starting to make some good ‘in roads’ locally to address this; but, this also means that brain injured children and their families will continue to experience prejudice, inequality and discrimination for some time to come until knowledge of acquired brain injury becomes more prevalent in the minds of all medical and community professionals. The current lack of awareness, recognition and understanding is enormous across all sectors and professions.
- 1.7** Probably the most significant factor that is not acknowledged across all multi-agency professionals, is the child’s potential for regaining lost skills and abilities post brain injury with appropriate levels of support. Old school thinking by medical professionals thought that as children’s brains were still developing and by being in the school environment, children would naturally regain lost skills and abilities. They now know this to be untrue; and agree that children need a level of support tailored to their individual needs and neurological deficits to maximise their potential. Unfortunately, this does not happen.

- 1.8 This raises the question about what kind of society have we become when we close our eyes to the complex needs of brain injured children and young people and we punish them and their families for neurological deficits that they have no control over and are not their fault.
- 1.9 Advances in medical practice means more and more children are surviving serious injury and illnesses; which leave them with complex and often hidden disabilities. As a result, disability now comes in many forms. Neurological deficits and dysfunction arising from acquired brain injury, probably has the biggest negative impact on a child’s life and long-term future. Yet these children and their families face discrimination every single day; despite the existence of the Equality Act 2010.
- 1.10 The Equality Act 2010 states:
You’re disabled under the Equality Act 2010 if you have a physical or **mental impairment** that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities. The known deficits of acquired brain injury provide a framework to states how acquired brain injury creates neurological impairments; however, it is the lack of understanding about the effects of acquired brain injury on a child’s developing brain, by the people who complete the assessments, that inadvertently exclude brain injured children and young people. This discriminatory practice must change through improved assessment of their needs and increased awareness raising.
- 1.11 It is widely acknowledged that acquired brain injury is the biggest cause of death and disability in children and young people. The incidence of paediatric traumatic brain injury alone exceeds all other neurological disabilities as shown in the table below. A report entitled, “**Nobody made the connection**” was produced for the Children’s Commissioner in October 2012 and states the reported prevalence of certain disorders amongst young people in the UK population per disorder are:

Autism	0.6-1.2%
Learning Disability	2-4%
ADHD	1.7 – 9%
Dyslexia	10%
Traumatic Brain Injury	24-31.6%

- 1.12 Far more young people have suffered a traumatic brain injury than those that have autism or dyslexia, and their issues are often more complicated and disabling. Yet there is little recognition and understanding of the problems suffered by a child that has sustained either a traumatic or non-traumatic acquired brain injury.

The Children’s Commissioner is now calling for better treatment for children and young people who are living with an acquired brain injury.

- 1.13** In the UK, few brain injured children and young people have experienced good outcomes, but where this has happened, it has only been through the resilience, hard work and determination of their parents; not the state. The poor outcomes that brain injured children achieve is the result of a lack of understanding and a failed state system. This must now change. It is the responsibility of public leaders and adult medical and other community professionals to keep up to date with emerging developmental problems in children and young people arising from an acquired brain injury; due to its high incidence and significance on a child's developing brain.
- 1.14** Parents are not provided with the information they need to be able to care for their child both effectively and safely; without which they are unable to be strong advocates for the complex needs of their child. They should be provided with detailed information about their child's brain injury; particularly the associated risks pertaining to the child's brain injury.
- 1.15** The findings of this project are shocking and show how brain injured children and young people and their families frequently suffer discrimination that excludes them from services that should be there to help them, down to a lack of awareness and understanding by public sector professionals; including the NHS professionals.
- 1.16** Brain injured children are:
- discharged with very little help or support available to them in the community because they are perceived as being fine
 - not included in the Register of Disabled Children held by local authorities;
 - refused access to services from Children with Disabilities Teams
 - refused Education Health and Care Plans
 - punished and excluded by statutory bodies
 - not helped and supported to achieve good outcomes post brain injury
 - labelled as being 'naughty children' and excluded from school
- 1.17** Their parents
- are refused carers assessment and access to carers breaks
 - are not provided with the important information they need at the point of discharge for hospital
 - but are then punished for the behavioural problems of their neurologically impaired children
- 1.18** It is hoped that the findings and recommendations outlined in report will:
- trigger a sea-change that will start to transform services and support for brain injured children and young people; and
 - that that South Tees CCG and other statutory bodies work with Matrix to improve services for families through co-production and support so that we start to deliver better outcomes for brain injured children and young people across the James Cook catchment area.
 - **Matrix provides an exciting opportunity for the Tees Valley to show some national leadership and work to improve service provision for brain injured children and young people.**

2.0 PURPOSE

- 2.1 The purpose of this report was to review the implementation of our Family Support Project against the initial aims set out in the original application. These were:
- a) The creation of an effective new community based service aimed at supporting parent carers with a view to improving mental health and building family resilience to cope with the impacts of acquired brain injury in children and young people;
 - b) Improved mental health issues in parent carers;
 - c) Provision of a coordinated approach to support faster and improved hospital discharge for children, young people and their families who are now coping with a 'different' child. (A child now living with neurological disabilities and acquired special needs)
 - d) Provision of long-term support for families of children and young people who are now living with a life-changing long-term condition.

3.0 INTRODUCTION AND BACKGROUND

- 3.1 MATRIX Neurological is an innovative children's charity based in Middlesbrough, established to provide practical help and support to children, young people and their families who are living with the effects of an acquired brain injury (ABI). The founder of Matrix created the organisation because of first-hand experience of child brain injury and the lack of appropriate and well-informed support services that are available for these children and their families. In 2010 her son sustained a severe brain injury. Despite engaging with several support organisations at that time, our Founder was unable to find any brain injury support service that met the needs of her child and her family.
- 3.2 MATRIX was established to try to bring about significant changes for brain injured children and young people as we feel those with the lived experience of paediatric brain injury are best suited to provide for the needs of these families.
- 3.3 Our mission is: *"to work to remove health inequalities for children & young people affected by acquired brain injury; and provide effective support to their families that makes a real difference"*.
- 3.4 We know there are approximately 300 children and young people who attend A&E in the North East every year with a head injury (Cardiff University, 2015). Many of these have poor recovery rates and health outcomes post trauma; (NHS England North, Transforming Trauma Rehabilitation, 2013). Head injury and trauma are the biggest causes of traumatic brain injury in children and young people. Illness is the cause of non-traumatic brain injury.
- 3.5 Research says that ABI has a significant psychological impact on families; resulting in family breakdown, withdrawal from services, unemployment, depression and a loss of self, which in turn leads to poor rehabilitation outcomes (Hockney, 2015).
- 3.6 Probably the most significant factor that is not acknowledged across all multi-agency professionals, is the child's potential for regaining lost skills and abilities post brain injury with appropriate levels of support. Old school thinking by medical professionals thought that as children's brains were still developing and by being in the school environment, children would naturally regain lost skills and abilities. They now know this to be untrue; and agree that children need a level of support tailored to their individual needs and neurological deficits to maximise their potential. Unfortunately, this does not happen.

- 3.7 Parents also play a key role in facilitating good outcome post brain injury; however, they are not provided with the information and tools they need to achieve this.
- 3.8 Based on everything we knew in January 2016, we submitted a funding application to create a new Family Support Service for child brain injury families across Redcar, East Cleveland and Middlesbrough. The need for the project originated directly from service user experience, has been confirmed by regional specialists and our previous project beneficiaries, and reaffirmed by national and regional research.
- 3.9 Ultimately our project aimed to improve family wellbeing and resilience and improve the rehabilitation process, and address poor health and developmental outcomes in children and improve mental health in parent carers. These problems particularly affect people from disadvantaged areas as they experience higher risk and incidence of brain injury and demonstrate poorer rehabilitation outcomes (Lequerica and Krch, 2014).
- 3.10 For many parents in this situation, they will be in a caring role for many years - if not the whole of their life. This project supports them to carry out their caring role and look after their own wellbeing.
- 3.11 As our project aims to improve family wellbeing and resilience and improve the rehabilitation process, we will address poor health and developmental outcomes in children and improve mental health in parent carers. Research shows that almost 18% of brain injury parent carers rate their quality of life as 'poor' or 'very poor', and 59% show signs of clinical depression. (Headway, 2012)

Project Foundations

- 3.12 Our Family Support Service is based upon a report by Ross Mackay; Principal Advisor to the Ministry of Social Development in New Zealand that was written in 2003. Into our project we embedded learning and recommendations for building family resilience from other countries that appear to be delivering better outcomes for disadvantaged children.
- 3.13 The report, entitled Family Resilience and good Child Outcomes, highlights the important factors surrounding family resilience. It states: *"a family can be considered resilient where it has encountered adversity and coped successfully with the challenge. This has led to a focus on family strengths – those qualities that allow families to cope successfully with challenges to their wellbeing."* Brain injury families need to be resilient to be able to cope with the ongoing challenges they face.
- 3.14 However, we have also taken this a step further and considered parent and child needs against Maslow's Hierarchy of Human Needs. We mapped physiological, safety, belonging and love, esteem, cognitive aesthetic and self-actualisation needs against the factors needed for building family resilience. These are shown below.

Maslow's Revised Hierarchy of Human Needs



[Abraham Maslow; (1943, 1954) *hierarchy of needs*]

Relevance of Maslow's Theory

- 3.15 Mackay's Report states there are a numerous processes that operate within families. These include – emotional bonds; effective patterns of communication, the use of coping strategies and family belief systems that influence how families cope with adversity and manage stress. Good interventions based on **a sound understanding of the problems**, assist in relieving family stress. The evidence provided in this report will show how existing services do not help brain injured children and their families because the problem is not understood in the first place. The problem is not the child or the parent's poor parenting style; it is the devastating and life changing impact of an acquired brain injury on a child's developing brain.
- 3.16 Maslow's seven stage model can also be divided into deficiency needs and growth needs. The first four levels are often referred to as deficiency needs (*D-needs*), and the top level is known as growth or being needs (*B-needs*).
- 3.17 The deficiency needs are said to motivate people when they are unmet. Also, the need to fulfil such needs will become stronger the longer the duration they are denied. For example, the longer a person goes without food, the hungrier they will become.
- 3.18 One must satisfy lower level deficit needs before ascending to meet higher level growth needs. When a deficit need has been satisfied it will go away, and we become directed towards meeting the next set of needs. Once these growth needs have been reasonably satisfied, a person may be able to reach the highest level called self-actualization. Resilience!

- 3.19 Maslow thinks that every person is capable (and has the desire) to move up the hierarchy toward a level of self-actualization. Unfortunately, progress is often disrupted by a failure to meet lower level needs. Traumatic life experiences cause an individual to fluctuate between levels of the hierarchy. Therefore, not everyone will move upwards through the hierarchy but may move back and forth between the different types of 'need'.
- 3.20 A traumatic life experience is what brain injuries families have experienced. It is therefore feasible to suggest that a family will not become resilient unless each 'need' is met. As such this project has explored the abilities of child brain injury families to ascend through the levels of need. This report will demonstrate how brain injured children and their families are being hindered in becoming resilient by the NHS and other public and private services due to a lack of understanding; which then justifies the need for our services and the need for a very different approach.
- 3.21 The outcomes as a result of our project were anticipated to be:
- Improved quality of life for people with long term conditions by helping families to learn and understand about their child's long-term condition
 - Focus on groups in need; i.e. Patients with long term conditions by helping parents to support and manage their child's health problem and enabling them to live in their own home
 - Supporting parent carers

4.0 FINDINGS

4.1 Before Matrix Neurological was established as a registered charity, much research and consultation was undertaken to justify its creation. Professionals tell us that lots of research has been completed pertaining to paediatric acquired brain injury; but nobody does anything with it. Matrix was founded as a registered charity to take the findings and recommendations and find effective solutions; however, the scale of the problem regarding childhood acquired brain injury is significant and the scale of need should not be underestimated.

4.2 The British society of Rehabilitation Medicine and the Royal College of Physicians acknowledge that a range of deficits can emerge following an acquired brain injury; as shown in the table below:

PHYSICAL	COMMUNICATION	COGNITIVE	BEHAVIOURAL EMOTIONAL
<p>MOTOR DEFICITS:</p> <ul style="list-style-type: none"> • PARALYSIS • ABNORMAL MUSCLE TONE • ATAXIA (co-ordination) <p>SENSORY DEFICITS</p> <ul style="list-style-type: none"> • VISION • HEARING • SMELL • TASTE <p>DYSPHAGIA (swallowing difficulties)</p> <p>SEIZURES</p> <p>OTHER:</p> <ul style="list-style-type: none"> • HEADACHE • FATIGUE • PAIN • SLEEP 	<p>LANGUAGE DEFICITS:</p> <ul style="list-style-type: none"> • EXPRESSION (finding the right words) • COMPREHENSION (understanding) • DYSARTHRIA (difficulty speaking) • DYSLEXIA (difficulty reading) • DYSGRAPHIA (inability to write) • DYSCALCULIA (problems with maths and calculations) 	<p>IMPAIRMENT OF:</p> <ul style="list-style-type: none"> • MEMORY • ATTENTION • PERCEPTION • PROBLEM SOLVING • INSIGHT • SAFETY AWARENESS/ RISK TAKING • SELF MONITORING • SOCIAL JUDGEMENT 	<p>DEFICITS:</p> <ul style="list-style-type: none"> • EMOTIONAL LABILITY (unstable emotions or emotional over-reaction) • POOR INITIATION • MOOD CHANGE • ADJUSTMENT PROBLEMS • AGGRESSIVE OUTBURSTS • DISINHIBITION • POOR MOTIVATION • INAPPROPRIATE SEXUAL BEHAVIOUR • PSYCHOSIS • DEPRESSION / MENTAL HEALTH (Our addition) • OCD (Our addition)

(Source: British Society of Rehabilitation Medicine (BSRM) and the Royal College of physicians (RCP); 2003

4.3 Deficits in any of the above domains can have a significant effect on a child's education, learning and development.

General

4.0 One of our big ambitions is to make the Tees Valley the best-informed region in the country about acquired brain injury in children and young people through awareness raising, so that we can start to address the significant inequalities that brain injured children experience every day. During the delivery of this project we have learned so much that needs to change regarding brain injured children and young people; but this is a huge task and will take years to complete. However, through this project we are now starting to make some good 'in roads' to address this; but, this also means that brain injured children and their families will continue to experience prejudice, inequality and discrimination for some time to come until knowledge of acquired brain injury becomes more prevalent in the minds of all medical and community professionals. The current lack of awareness, recognition and understanding is enormous.

Brain injury and NHS staff

4.1 Families tell us that NHS staff do not explain acquired brain injury to them very well. Families are often left knowing their child has a brain injury, but they do not know where in the brain; how it will affect them; how it links to child development problems; and what that means for their child. We appreciate that Consultants time is limited so using the scant medical information that families have, we now provide the explanations that families need.

4.2 The mechanics of the brain injury are also not explained to parents. Medical staff should be aware that the effects of a head or brain injury are not always directly related to the initial physical injuries to the brain. They can be both widespread and significantly debilitating. In the community parents are expected to have the most knowledge about their child. Changes to local authority processes mean they must make choices based on the needs of their child. How can they do this when:

- a) they don't understand what has happened inside their child's head; and
- b) problems and issues are yet to emerge or are still emerging?

Parents need to be provided with all the information they need to be able to make informed choices and appropriate decisions for (and with) their child. Without our support, they are unable to do this.

4.3 Often discharge letters contain very little detailed information for parents and are written more for other medical professionals, i.e. GP's; and not parents. Parents often struggle to understand the terminology and context of the letters. However, what is even more important for families, other medical professionals involved in the child's care, as well as other relevant community professionals, should be aware of the associated problems and risks pertaining to a child's brain injury and any potential issues that may emerge in the future. Without this information, everyone is left in the dark; which then leaves a brain injured child vulnerable and at risk. Local authorities are not meeting their statutory duties towards these children when they are not even included in the Register of Disabled Children.

4.4 Our involvement with local authority Early Help Teams is repeatedly highlighting this issue. The problems that families are experiencing of changed child behaviours are often not related to a child's brain injury which may have occurred up to ten years earlier. This also links back to the unclear Discharge Letter and the lack of information provided to parents by Consultants. This means that the complex needs of these children are not understood, supported or met; which is discriminatory and contributes to the poor long-term outcomes for brain injured children.

- 4.5 Families have tremendous respect for the medical staff that have cared for their child; however, they also express concern at the level of negativity often portrayed by medical professionals. Whilst it is acknowledged that it is impossible to predict a potential long-term outcome, there are lots of positive factors that contribute towards a good recovery for children and these should be acknowledged. Consultants don't ask any questions about the child before the injury; yet there are important pre-injury factors that can contribute to a positive recovery.
- 4.6 These positive factors are also much wider than current NHS provision. i.e. physiotherapy, OT, SALT and Neuropsychology etc. Whilst these services are important to aid recovery; so is the ongoing physical, emotional, psychological, cognitive development of the child; hence pre-accident abilities are important. Unfortunately, post discharge families tell us they are often left 'in limbo' and feeling their situation is hopeless. These feelings can have a significant impact on parent wellbeing post discharge and contribute to poorer long-term outcomes for the child as a result.
- 4.7 Families have told us these feelings are further exacerbated as very little age appropriate neuro-rehabilitation therapy is provided by the NHS in the community. Children and young people often complain that NHS professionals make everything too clinical and boring. Nor do the activities relate to their lives and the real world. This is something that Matrix can help both children and families with, through the creation of community based sessions for brain injured children and young people. Making neuro-rehabilitation activities 'fun', will encourage children to engage with and enjoy their neuro-rehabilitation 'therapy'. This was evidenced in a recent news item whereby children and young people affected by Hemiplegia were taught magic tricks instead of doing physiotherapy. Significant functional improvements were made and the children had participated fully in their 'therapy'.
- 4.8 Whilst there are activities that can be done with adults, such as those contained in The Brain Injury Workbook written by Trevor Powel; nothing currently exists for children. However, we know that children learn through play. Our charity now has a range of fun activities that can be tailored to age, ability and individual need, that can be used to help children to recover and regain lost skills and abilities post injury. This creates an exciting opportunity for us to develop a new service to help children to achieve better outcomes post injury in the community. It will also help to remove the social isolation that many brain-injured children and young people experience.
- 4.9 Families do not receive a neuro-rehabilitation plan. They tell us that any plans that community therapists are working to are agreed internally with little or no involvement or consultation with parents. The approach is often very piecemeal, not individualised, and families are often unaware of any holistic recovery aims or neuro-rehabilitation goals that have been set for their child by the NHS team. Parents should be included in this process. They know more about their child and their pre- and post-injury needs and abilities than anyone else.
- 4.10 Surprisingly, we have also learned - that nursing staff often do not appreciate that a range of childhood illnesses are also a major cause of child brain injury. Staff assumed brain injury was only caused by a trauma type head injury. i.e. Assault, road traffic accident, falls etc. They did not realise that acquired brain injury includes a range of causes; such as meningitis, encephalitis, brain tumour, stroke, cardiac arrest, suffocation, asphyxiation, near drowning etc. As such this indicates that more awareness raising could be done both through under-graduate programmes at university and staff learning and development training within the NHS.
- 4.11 During this project, we also consulted with paediatrician and nursing staff to obtain their views on the need for our services. They responded:

NEED	
FAMILY SUPPORT SERVICE	HIGH/V HIGH
CASE MANAGEMENT SERVICE	HIGH/V HIGH
SERVICE NAVIGATION	HIGH/V HIGH

Brain injury and multi-agency Teams

4.12 We have also found there exists no multi agency neuro-rehabilitation plan to address **ALL** the needs of the child. There is a piecemeal approach. This leaves non-medical professionals that participate in MDT meetings, not fully understanding the needs of brain injured children. As such there is often a disorganised approach to service provision and care commissioning; which is often not conducive to neuro-rehabilitation aims. Few of these children have their needs met under the new Education Health and Care Plans as acquired brain injury and its complex effects on an individual are not recognised or understood by a range of professionals. Unfortunately, in many cases brain injured children are often refused EHC Plans unless there is a physical or other evident disability. Changed or emerging needs caused by neurological deficits resulting from a brain injury are not accepted or recognised as a disability. This issue then has significant impact on outcomes for brain injured children and young people and their parents and carers.

4.13 Disability Living Allowance

Brain injured children are eligible for DLA depending on their individual needs and the changes that have occurred as a result of their brain injury. Child brain injury is classed as a disability for benefit purposes. Some of our children are in receipt of DLA, other families do not even know that they are eligible to claim it, despite their child having had a brain injury and may now have significant neurological deficits impacting on their normal child development milestones. This should be addressed as part of the discharge planning process, which does not appear to happen. Matrix ensures they do claim DLA for a brain injured child and we assist families with the application process. However, this does not then translate into local authority teams and processes, including Carers Assessments and EHC Plans.

Carers Assessments

4.14

The NHS states:

“If you are a parent of a disabled child aged under 18, your child can be assessed by the local authority under law relating to the needs of children in the Children and Families Act 2014.”

You will also be assessed as part of that process because social services will look at the needs of the family as a whole. This is often referred to as a "holistic" assessment.

The assessment should take into account detailed information about your family, including:

- the family’s background and culture
- your own views and preferences
- the needs of any other children you have
- The assessment is not a test of your parenting skills, but should be a sensitive look at any difficulties the family has as a whole, with a view to considering what support or services are needed.

A care plan should be drawn up that would include services to benefit both you and your disabled child. For example, there could be adaptations to the home, help with bathing or regular respite breaks to ensure you get the rest you need. You could also choose to have a direct payment so that you can buy in your own services for your child.

- 4.16 Unfortunately, unless a brain injured child is left with a co-existing physical disability, child brain injury families are left excluded! Brain injured children should be entitled to these services too, particularly as the neurological deficits caused by an acquired brain injury is a recognised disability by the government for Disability Benefit purposes. We have children who are in receipt of DLA, who are not considered as having a disability by local authority professionals; are not included in the Register of Disabled Children; nor have they ever had an EHC Plan, despite them not meeting their expected development milestones.
- 4.17 Sadly, we find that **none** of our parents have received a Carers Assessment, despite being entitled to one. This is a significant failing in the system. On one hand paediatricians talk about brain injury being a complex hidden disability that can leave children with a range of deficits and they are aware of the impact child brain injury has on parents and family wellbeing as a whole; but they do not acknowledge the ongoing disabling effects of a life-changing acquired brain injury during the discharge planning process. This means that children and young people are being discharged from acute settings with complex needs that are not understood or provided for. Parents state they are 'just left to get on with it by everyone', leaving the family unit at significant risk of increased stress or breakdown, and the child's needs not being met.
- 4.18 Families have also reported negative experiences with the Child and Adolescent Mental Health Service (CAHMS). It seems that brain injured children are often automatically referred to CAHMS by GP's and Social Workers if they are any presenting with behavioural issues. However, we are told that CAHMS do not understand acquired brain injury. Most of our children have been through the CAHMS process; sometimes more than once without a final diagnosis or any positive outcome being made for the child because the underlying problem has not been recognised and appropriate support measures put in place.
- 4.19 Parents are frequently sent on parenting courses because the child's behaviour is considered 'their fault'. We are working with one family whose child has been under the CAHMS service for 10 years and although Mum has completed several 'Parenting Classes', the child has made no progress at all because the underlying problem – i.e. a brain injury – has not been recognised and the appropriate rehabilitation and support mechanisms put in place.
- 4.20 It seems CAHMS do not ask parents any questions about previous head or brain injury injuries. Parents tell us that any behaviours displayed by the child that are consequent to an acquired brain injury are often ignored, missed or misdiagnosed. They are frequently told by CAHMS "you are doing everything right" but they then feel they are then punished by Social Workers and are sent on another Parenting Course. Some of our parents have been made to complete more than one parenting course! This only adds to more stress and pressure on parents.

4.21 We have also learned that brain injured children are referred for assessment after assessment from one service to another; with no diagnosis made at the end. Parents are disclosing the same information over and over again, which is both stressful and unhelpful. We are working with one family whereby the child has been assessed by **ten** different organisations and has had **fifteen** assessments by different professionals; however, 7 years later they still do not have a diagnosis and nothing has changed for the child. This leaves families angry and frustrated which then impacts on their own wellbeing and exacerbates family pressure.

4.22 In addition, many parents don't sleep well; rarely wake up feeling refreshed; don't have time for their own interests and hobbies; rarely see their friends and generally don't have time to look after themselves. Their caring responsibilities can take up all their time.

Local authority staff

4.23 It is widely acknowledged that acquired brain injury is the biggest cause of death and disability in children and young people. The incidence of paediatric traumatic brain injury alone exceeds all other neurological disabilities as shown in the table below. A study was completed by McKinley et al, 2008; McGuire et al, in 1998.

4.24 A report entitled, "**Nobody made the connection**" was produced for the Children's Commissioner in October 2012 and states the reported prevalence of certain disorders amongst young people in the UK population per disorder are:

Autism	0.6-1.2%
Learning Disability	2-4%
ADHD	1.7 – 9%
Dyslexia	10%
Traumatic Brain Injury	24-31.6%

Far more young people have suffered a traumatic brain injury than those that have autism or dyslexia, and their issues are often more complicated and disabling. Yet there is little recognition and understanding of the problems suffered by a child sustaining a traumatic or acquired brain injury.

The Children's Commissioner is now calling for better treatment for children and young people who are living with an acquired brain injury.

4.25 However, from our review of local authority strategies, we have learned that childhood acquired brain injury and its associated pressure on parent carer health and wellbeing remains unacknowledged anywhere! We have included six Case Studies in this report which highlight how brain injured children and their families suffer discrimination and health inequalities without the specialist help and support of MATRIXNeurological.

4.26 Additionally, medical professionals agree there is a direct correlation between poverty, deprivation and paediatric brain injury. The higher the levels of deprivation; the higher the incidence of brain injury. The Tees Valley has some of the highest levels of deprivation in the country. As such it is reasonable to assume that up to 31.6% of our young people population may be living with the effects of an acquired brain injury ranging from a mild to severe deficits. New research is showing that the severity of the initial brain injury does not determine the severity of the effects; meaning a child with a perceived mild head injury may have suffered significant deficits as a result. Very few of our children have received a medical diagnosis leaving their neurological disabilities misunderstood with their needs not being provided for.

4.27 Based on the latest population statistics provided by the Office for National Statistics (ONS) on the Tees Valley Combined Authority website, there are 160,900 children residing in the Tees Valley (including Darlington). **If** the Children’s Commissioners statistics at 31.6% of the reported incidence of traumatic brain injury is correct, of all the children and young people living in the Tees Valley, this could equate to approximately **50,844 children and young people** who are potentially living with the effects of an acquired brain injury, whose complex needs are unrecognised and supported. This could therefore be a significant public health issue that is currently being ignored; which may have a significant impact on the need for future health and social care services.

4.28 It would also be wrong to label brain injured children as having mental health issues. Poor mental health may also be a consequence of brain injury due to the lack of understanding and support brain injured children receive. But it is just that – a consequent effect. Simply treating the emerging mental health issue will not resolve the child’s underlying deficits. An acquired brain injury is a lifelong condition. Damage to a child’s developing brain has wide reaching implications for the child. Damaged neurological tissue does not usually regrow or heal. The deficits caused by brain injury are a life-long condition. However, through ‘neuroplasticity’ it is now known that brains can rewire and adapt to changes that have occurred within; but this will not happen without individually tailored support aimed at facilitating this. It is the responsibility of adults to give brain injured children the best possible chance of a good recovery and improved long-term outcomes.

Children with Disabilities Teams

4.29 Brain injured children are not recognised by local authority staff as having a disability. A child diagnosed with Autism, learning disability, ADHD or Dyslexia is, as is a child with a physical disability. The factors of disability that can have a significant impact on a child’s life, now comes in many forms. Neurological disabilities, such as acquired brain injury, are no less important and have a greater impact on physical and neurological functioning. Paediatric acquired brain injury should now be acknowledged and recognised.

4.30 Parents often ask us why it is so hard to get a medical diagnosis for their child’s problems and why nobody listens or wants to help their child. We all struggle to understand why the needs of a child with Autism or ADHD take precedence over a sudden life-changing traumatic event that has occurred to a previously normal healthy child that is now living with an acquired brain injury?

4.31 Also, because neurological impairments suffered by a brain injured child are often not acknowledged as being a disability, their parents received no support at all. Many do not receive a Carers Allowance, nor do families have any access to carers breaks or summer play schemes for their disabled children. We have recently heard that currently Middlesbrough Council will not accept Carers Assessments for carers of brain injured children; nor will they readily accept brain injured children when referred, unless there is an obvious physical disability or sensory loss. These children and their families therefore face discrimination once again.

Brain injury and Schools

4.32 Families say it is the cognitive, emotional and behavioural issues that cause the biggest disruption to family life. They are also the biggest issues that affect a child’s successful integration/reintegration into school as well as their academic outcomes. Invariably brain injured children will have some neurological deficits that affect these three essential human functions. Unfortunately, a lack of understanding in schools means brain injured children are often excluded from school and as a result; are punished again.

- 4.33 In a meeting with the Chair of Middlesbrough Council's Local Safeguarding Children Board in 2016, we were told that the Middlesbrough has the highest school exclusion rate of children and young people in the country. Could this indicate the direct correlation between deprivation and brain injury highlighted elsewhere in this report?

Brain injury and Child Safeguarding

- 4.34 We have also learned that child safeguarding procedures are failing brain injured children and young people. We are concerned that the accepted behaviours portrayed by a child that has been abused; could also be the 'normal' behaviours of a brain injured child that is not being abused. In 2016 these concerns were raised with the Chair of the Local Safeguarding Children Board in Middlesbrough Council in the hope that the Tees Procedures will be reviewed and revised. We have asked that at key points staff are prompted to ask and consider the possibility of a child having had a traumatic or non-traumatic brain injury as the result of an accident or illness. If this question is never asked – the true cause of a child's behavioural problems or vulnerabilities may never be correctly identified. This is highlighted in our Case Studies.

- 4.35 The safeguarding needs of brain injured children also need to be prioritised. Communication, cognitive, emotional and behavioural deficits in these children leaves them vulnerable, but their complex safeguarding needs remain unacknowledged and recognised. Moreover, they are more likely to be punished for the disabling factors pertaining to neurological disability. Punished for something that is not their fault as highlighted in Case Study 3.

- 4.36 The actions of other professionals also have an impact on child brain injury families and parent carer wellbeing. We are working with families where parents tell us they have been threatened with being fined - or worse still - arrested or having their child taken into care, because of the behaviours of their neurologically impaired child. Parents frequently tell us they are not listened to or believed by community professionals because often there is no recognisable disability.

- 4.37 It appears it is not uncommon for parents to be blamed and punished for the 'unacceptable' behaviours of their brain injured children; when they have not been provided with a proper diagnosis, any detailed information or offered any help or support. This also leads to increased family stress and parental burden. Toxic stress in the new term being highlighted as the cause for all behaviours in children and young people. It is easy to see how the parent carers of brain injured children will once again be labelled and blamed and their child's disability needs will remain unrecognised and unmet. These families need to be helped and supported; not punished.

Brain injury and the criminal justice system

- 4.38 It is not uncommon for acquired brain injury to create significant deficits in physical, communication, cognitive, emotional and behavioural aspects of neurological functioning. All factors are essential for successful integration into society. It is so easy for brain injured children and young people to fall into the criminal justice system where they display significant emotional and behavioural problems; which are sometimes significantly exacerbated by frustration on their part; and a lack of understanding on the part of others.

- 4.39 In 2016, a report was produced entitled "National Prisoner Healthcare Network: Brain Injury and Offending", following a joint study undertaken between NHS Scotland and the Scottish Prison Service. There was recognition of a need to better understand the health needs and services required by people with brain injury who are involved in the Criminal Justice System (CJS).

- 4.40 Impairments in cognitive functions (such as memory and solving problems) and in personality or emotional control (such as impulsivity, aggression, intolerance and lack of concern for others) are common after severe brain injury and are associated with neuro-behavioural changes that can easily lead to rule breaking and involvement with the CJS. As persisting outward signs of brain injury are rare, antisocial behaviour is often not attributed to the brain injury, and appropriate interventions that may reduce recidivism are not offered, or the ability to benefit from prison treatments that address offending behaviour is compromised.
- 4.41 The study found that the prevalence of head injury across the 8,000 inmates in Scottish Prisons that require intervention or support as a result of head injury are not known. Two meta-analyses of the literature suggest that the prevalence of head injury in offenders is 50% (Farrer and Hedges 2011) and 60% (Shiroma et al 2010).
- 4.42 The head injuries we most commonly encounter are caused by falls and assaults (Thornhill et al 2000). The risk is higher in young children, young adults and older adults and in those who have backgrounds of social deprivation and alcohol abuse. Longitudinal research in Glasgow has shown high rates of disability and elevated rates of death for up to 15 years after head injury, with risk of late mortality being especially high in younger adults (McMillan et al 2012, 2013, 2015; Thornhill et al 2000; Whitnall et al 2006).
- 4.43 Impairments that are common after head injury include cognitive deficits in concentration, memory, flexibility of thinking, solving problems and planning and personality or emotional changes reflected as impulsivity, irritability, aggression, impatience, intolerance, egocentricity, poor judgement, impaired insight and lack of concern for others. Of particular relevance to the Criminal Justice System, is the association between head injury and aggression, violence and more generally emotional deregulation (Wood 2001; Baguley 2006; Wood and Williams 2010).
- 4.44 It is important to note that in the context of head injury **persisting disability is commonly 'hidden'** as it derives from these cognitive and emotional changes that impact on day to day life and **more obvious physical disability is considerably less common**. Hence, in most cases there is no obvious outward sign of the head injury within a few weeks or months of the injury and the individual with a head injury and those that they interact with may not attribute their behaviour or difficulties to this injury. Hence, neither the head injured person nor those in contact with them make adjustments or allowances for the brain injury.
- 4.45 About 90% of hospitalised head injuries are classified as 'mild' and from which a good recovery is expected. **However, one of the most significant risk factors for having a head injury is already having sustained a head injury** (Nordström et al 2013) **and repeated head injury tends to have cumulative negative effects associated with long term functional deficits** (McKee et al 2009).
- 4.46 Another 'special case' might be made for those who have a brain injury in childhood; the brain and particularly the 'social brain', continues to develop until around the age of 25 and there is evidence to suggest that early damage can negatively affect social development (Lenroot et al 2006).
(Source: NHS Scotland and The Scottish Prison Service; NPHN BI and Offending Final Report: 21.03.16)
- 4.47 It may also therefore be feasible to suggest that the incidence of traumatic brain injury in inmates within the Scottish Prison Service may also be the direct result of a failed system within the statutory sector.

Family Support Activities

- 5.0** The job purpose, role descriptions and duties work well, but more Family Support Workers are needed to support the diverse and often complex needs of families and provide the ongoing practical and emotional support they need as the result of a complex and unknown recovery journey and coping with an unstable disability where new issues continue to emerge.
- 5.1** There were also some additional unintended benefits of the Family Support Project for the NHS. These were:
- Enabling families to attend hospital appointments by providing transport for parents without which they would have struggled to get there
 - 2 parent carers being referred for psychological therapies, that would not have happened so quickly or smoothly thus enabling faster access to services
 - Children being referred back into NHS services for medical treatments they were not previously receiving (See all our Case Studies)
 - Transporting parents for holistic therapies -that we were providing with grant funding from other sources – which have helped to relieve parental stress and anxiety thus improving general wellbeing.
- 5.1** When the Family Support Worker commenced, we already had two very complex families that we were working with. Both families had a young child that had sustained severe brain injuries which had left them with significant neurological deficits. Both families were struggling to cope with the life changing events that had occurred with their child.
- 5.2** From the personal experience of our Chair and research that we undertook, we knew that mental health issues significantly affect parent carers of brain injured children. In turn, this has a ripple effect on the family unit as a whole. A brain injury can have a disruptive impact on family 'norms' as families struggle to adjust to the changes that take place. This also affects other siblings and often this leads to behavioural issues with siblings, family breakdown and divorce.
- 5.3** Where Matrix Neurological is involved with families, we conduct baseline assessments of parents/carers and review progress regularly. We know that our work helps to minimise the negative stressful effects on a family. The majority of our parents are showing improved mental health as a direct result of our support when compared to their baseline assessment. Whilst we acknowledge it is still very early days, tensions in family relationships are being minimised.
- 5.4** Where we have not been involved, i.e. with families we are engaging with at a much later stage in their child's recovery journey, we have found that these families are often involved with local authority Early Help Teams due to emerging issues with children. Parents are struggling to cope and don't know where to turn for help. Everyone lets them down.
- 5.5** These families are increasing in numbers. As such we are now receiving referrals from teams in Redcar and Cleveland, and Middlesbrough Councils who have concerns with 'problem families' and failed interventions with other services that have failed to deliver any change for the child or the family. Case Workers are often at a loss where to turn to next for help with these vulnerable and often complex families. They now refer them to us; however we need more financial support to be able to meet demand because each case is complex and takes time to investigate. We are now receiving referrals from the public, private and third sectors.
- 5.6** To help parents to understand more about acquired brain injury in children and young people, we

have created a number of useful tools to help families. First, we obtained some funding to create a short-animated DVD that explains brain injury in a simple way. Several copies have been donated to the children's wards in regional Major trauma Centres for use with families. The DVD has had some excellent feedback from medical professionals and families. All of the families referred to us are provided with a free copy of the DVD, which can also be shown to other relatives, friends, school etc. to help improve understanding.

- 5.7** Second, we created a brain injury assessment tool based on the known deficits of acquired brain injury acknowledged by the British Society of Rehabilitation Medicine and the Royal College of Physicians. This is helping to identify problems that children are experiencing, including problems that have been missed by other medical or community professionals. The feedback we are receiving from Consultants is that it provides a very helpful overview of a child's problems and helps to justify the need for a referral back into children's outpatient services. It also helps to alert Consultants to other problems that may have been missed, overlooked or are emerging, so children can be referred to other appropriate services for treatment during their review appointments. i.e. Audiology or Ophthalmology. More information regarding the benefits of this approach is provided in our Case Studies.
- 5.8** Probably the biggest benefit of our brain injury assessment tool is that we can obtain a simple baseline assessment of a child's problems and measure the level of change that has occurred. Our baseline assessment also enables us to monitor any changes; good or bad; that are occurring which then enables us to highlight emerging issues to Consultants to obtain their medical opinion. If the Consultant agrees, children can then be referred back to the NHS for further treatment. Our parent self-assessment forms also work in a similar way.
- 5.9** Finally, our Welcome Pack created for families, contains some general facts about brain injury which can also be added to. In time, it will contain the detailed information they need pertaining to their child's brain injury and the impact it has on their neurological functioning so that the brain injury stays foremost in everyone's mind. We do not overload parents with medical or generic brain injury information as it is not helpful. Our priority is to ensure it contains the important information relating to their child's individual needs.
- 5.10** As mentioned previously, when a traumatic brain injury occurs in a child or young person, it is not uncommon for a parent to experience symptoms of PTSD. These symptoms often go untreated and unsupported until things reach crisis point within the family unit. Parents can also be extremely angry about the cause of the injury; particularly where another person has caused the brain injury. Alternatively, they experience significant levels of guilt or even anger if for example a child suffers a serious head injury as the result of a fall from a height or even from falling of a bike or skateboard etc. and was not wearing a helmet. These issues have also been prevalent with those families who have not had the benefit of our services during the early stages. The 'blame' or 'labelling' approach taken by multi agencies further exacerbates stress and frustrations.
- 5.11** When Matrix are involved with these families, we have been able to provide emotional support and talk to parents about their feelings. We also help them to reflect on their journey so far. Parents of brain injured children are often extremely vulnerable. Frustrations and emotions run high. Talking to someone who experienced something very similar helps them to feel less alone and to come to terms with what has happened. The shared journey that we offer also helps to build confidence. In turn, this helps them to let go of any perceived guilt and enables them to focus on the child's recovery instead; whatever that may be. In particular, it seems that emotional support from a Peer Mentor

helps them to aim for a good outcome, which in turn helps to reduce anxiety and fear of an unknown future.

- 5.12 The nature of the child’s injury and its cause plays a significant part in how parents cope with the life threatening and critical situation they often find themselves in. Whilst the family is supported by medical staff inside the hospital; once the child is discharged, both the support and the daily therapy they need ends. The tense situation at home is then further exacerbated because bringing a brain injured child home from hospital is extremely stressful for parents; which is why they need our support.
- 5.13 We do not helicopter in and out again, never to be seen again for months. We get involved and build a relationship with the family with a view to alleviating as much stress and burden as possible so that they can concentrate on caring for their child’s needs and start to care for themselves. Some of our vulnerable families may be visited 2-3 times per week; depending on their assessed need and other emerging family issues.
- 5.14 Through engaging with families much earlier in their journey, we have been able to participate in the discharge planning process whilst also providing emotional and practical support to the parents to facilitate improved confidence. Parents take comfort and are reassured, in knowing we will be there with them ‘on the outside’ to support their coping abilities. Being local and having more staff resources also means we can visit them more often.
- 5.15 Where Matrix have not been involved in the early stages, we find parents in extreme emotional distress often living in a constant ‘fight or flight mode’; which is then detrimental to their health, well-being and day-to-day coping mechanisms. This then leads to a heightened state of stress and burden on the family; which is counter-productive to the needs of the brain injured child and adds to the existing pressure experienced by siblings and other family members.

5.16 It is well recognised that ABI affects not just the injured individual, but the whole family. Immediately after their child’s injury, families experience common emotional reactions, including panic and fear, shock and denial, anger, guilt, isolation, and hope. Although many families eventually adapt favourably to the increased demands of the injury, it is also common for parents of children with ABI to experience high levels of parental burden, psychological distress, and deterioration in family relationships which can persist for as long as 3 years post-injury. Emerging behaviour problems and concerns about the child’s ability to function independently may drain family resources and coping abilities. Furthermore, the high levels of stress observed amongst parents of children with ABI may also contribute to marital breakdown.
 (Source: Jade West; Cerebra; Acquired brain injury in children and young people; 2010).

5.27 Throughout this project we have found all the above issues to have existed within families. Through partnership working with staff in the Children’s Wards in James Cook Hospital, we have been able to engage with families prior to discharge and support them through a significant period of emotional and psychological adjustment. In turn, this helps to reduce the negative effects of brain injury on the whole family unit by alleviating ‘the fear of the unknown’. We continue to support these families through uncertain times.

- 5.28 Every parent has told us that being able to talk to someone who has found themselves in a similar situation helps them tremendously; particularly when there has been a positive outcome for the family unit. This gives these families hope, courage and strength. Our project is also addressing the negative impacts of ABI across the entire family and helps to create an 'optimum environment' for a child's rehabilitation. Without our project, this does not happen and the child and family's health and wellbeing suffer as they attempt to cope with, as one of our service users said, "a life shattering experience."
- 5.29 We are increasingly receiving referrals for children who have had head injuries up to ten years earlier. This is an area that we did not really anticipate and there is an increasing demand for this service from families and local authority teams. These children have no formal brain injury diagnosis and this work is time consuming, requiring investigation, reading and coordinating years of reports and documents.
- 5.30 Some of these children have missed their expected development milestones but their problems have not been correctly identified or supported. For other problems that emerge they appear to be significantly escalating as they move in to secondary school and/or puberty. Brain injured children find it hard to make the transition into their new environment and the way secondary schools function with timetables and lesson plans. It is at this key stage of brain development that their cognitive and executive skills deficits become more apparent when compared to their peers.
- 5.31 Since this project commenced we have also seen an increase in the demand for our services from a range of families. This includes families' north of the Tees and adult members of Headway. We know how difficult it is to access appropriate help and support for brain injury families so we have supported these families also; albeit in a slightly different way and less intensively. However, this also highlights how the families of adult brain injury survivors, are also not well supported appropriately in the community. Existing statutory, private and VCS provision does not understand or meet need.
- 5.32 In response, our support has extended to the Yorkshire Dales and Gateshead and Sunderland; although not funded by this project. However, this does demonstrate the demand for our unique support services and confirms a distinct lack of services providing what is 'actually needed' by brain injury families; regardless of what other support is provided.
- 5.33 As a result of our help and support these families:
- Have a better understanding of acquired brain injury and its complex effects on the individuals
 - They feel better able to cope

CASE STUDIES

6.0 Case Studies

- 6.1 We have provided some case studies as an example of what we have done and the difference we have made. The Case Studies selected are not extreme examples. They represent the norm of family experiences. Further Case Studies can be provided if required.

Case Study 1 – ‘A’

A is 12 and recently moved into the area. The child sustained a traumatic brain injury when they were six months old. The family were referred to us via another VCS organisation. We found the child has significant neurological impairments and associated health needs that were untreated. Dad is suffering from PTSD as a direct result of what happened to his son. Mum was under immense pressure.

We met with the family and with the information provided by the parents we completed a Brain Injury Assessment on the child. This identified numerous neurological deficits that the family were previously unaware of. During our conversation with the parents it emerged that the child also has vision problems related to his brain injury. We explained what had happened to the child during the incident that caused the brain injury which helped them to understand what had happened inside the child’s head and why new issues are emerging now.

Health

This information has enabled the family to have the child referred to the appropriate paediatrician. The child is now receiving medical treatment for issues, some of which were previously unknown and not treated. A has now been referred to Ophthalmology Services in James Cook and is also being reviewed regularly by a paediatrician so that any ongoing health issues will be addressed.

Social Care

A is not registered as a Child in Need with the local authority and we are working with the Early Help Team to support the family. The child is socially excluded, has no friends and spends any free time with parents and other adults.

Education

A has significant learning disabilities and has not met any of the expected development milestones. They had a SEN Statement which - in the new school - was being transferred to an EHC Plan. However, the document had failed to address the emerging health and SEN needs associated with the brain injury. We contacted the school to arrange a meeting which we attended with Dad to help him to explain the child’s needs. The professionals present were shocked at the issues we had identified and how they would significantly impact upon the child’s learning without appropriate support. Interestingly the child’s teacher felt A’s problems all now made sense! These issues have now been built into his EHC Plan.

The family are also now receiving emotional support and regular visits from the Family Support Worker. Dad is now receiving Psychological Therapy for his PTSD and he is receiving 1-1 emotional and practical support from us to help him move forward. He has a Support Plan with us and he is working towards some identified goals. The family told us:

“We are so happy to have found this service. We are getting so much more help and support – more than we have had in 11 years. You are not only helping us but you are helping our child.”

Case Study 2 - B

B is 11 and was involved in a road traffic accident. They sustained a traumatic brain injury. Since the child's discharge from hospital to home several months ago, the family have had no help or support. They did not understand what had happened inside their child's head and this has significantly impacted upon the health and wellbeing of both parents; particularly Dad who is showing signs of PTSD and severe anxiety. Mum was becoming depressed worrying about everyone else. The family were referred to us for help and support by their solicitor.

B was born a normal healthy child following a normal delivery. The child was bright and attained high grades in the Yr6 SATS.

Health

We met with the family at home and with the parents and the child and we completed a brain injury assessment on the child. The child also lacked awareness and understanding of the effects of the brain injury. They perceived themselves to be 'fine' which is inaccurate. The assessment identified lots of issues and risks and potential issues that may yet emerge. The family now understand how their child's brain injury is affecting their child and are aware of the dangers and risks they need to manage.

Working with medical professionals we explain the mechanics of the brain injury and how that relates to the changed child they now have. Our assessment also identified a number of medical issues that were not being treated. We discussed these with the paediatrician and medication has now been prescribed and other emerging issues are being addressed.

Education

B returned to school for a few weeks before the summer holidays with no support in place. Nor did the school understand the child's changed needs. We discussed our concerns with the family. We also discussed these with the Consultant who agreed with our concerns.

We contacted the school to discuss the child's changed needs and other safeguarding issues. The consultant and the family agreed that the child cannot return to school until these issues are addressed and the new SEN needs are supported effectively.

The meeting was held a few weeks ago and B has now returned to school on reduced hours. These will increase slowly over the next few weeks whilst monitoring the impacts and risks on the child. The goal is to get B attending school for normal hours whilst ensuring they are participating fully and getting the most out of school. The school are now fully aware of the child's needs and a detailed risk assessment is now in place. Regular review meetings happen every two weeks. Feedback so far is that the child is reintegrating well and is now attending school for an extra hour each day.

Feedback

From the school to the parents

"They know so much. We didn't know anything. We have never had such detailed information about any child returning to school after an accident or injury. It was really helpful. We will set up regular meetings to review progress."

Social Care

The child has **not** been referred to the Children with Disabilities Team and we have helped the family to apply for DLA for the child.

The family are now receiving regular support visits from us and Dad is now on medication prescribed by his GP and he has been referred for Psychological Therapy.

Feedback from the parents - ***We don't know where we would be without you. You have told us about so many important things we weren't even aware of.***

Case Study 3 - C

C is 6 years old and was born following a normal delivery with no complications. C had been a healthy baby and toddler. Mum contacted us and self-referred the family. She was in a desperate mental state. We responded immediately and visited the family.

Although this mother was extremely distraught, she was very open about all the complex issues surrounding the family and the events pertaining to the child's accident. She was also extremely anxious because she was being blamed for the child's behaviour by Social Services.

With Mum's help we compiled all the reports and information she had and we investigated the events that had occurred.

It transpired that the child had been involved in a road traffic accident when aged 4. They sustained significant head and other physical injuries; including multiple brain bleeds. They required emergency life-saving abdominal surgery and transferred under blue lights by road ambulance to Newcastle. The child was critically ill and remained in PICU for several days post-surgery; before eventually being transferred back to James Cook University Hospital.

Health

In the discharge letter, the Paediatric Consultant had provided information about the brain bleeds and had stated that the child had gone on to make a good physical recovery. There was no mention of the neurological impairments caused by the serious brain injury that had been sustained.

At the time of meeting this family which was almost two years after the accident, this child had not received any neuro-rehabilitation to support his ongoing neurological recovery.

Social Services

Mum told us that a social Worker had been appointed and had attended several MDT meetings in James Cook Hospital, at which the child's injuries and needs were discussed. The person was also present at the Discharge Planning Meeting.

Post discharge, none of the services that were promised to the family were provided. Nor was any physiotherapy or occupational therapy provided.

When Mum questioned this, the Social Worker had stated (many times) that the child was fine and there was nothing wrong with him. As such they were not entitled to receive any additional services.

We attended a meeting with Mum and the Social Workers present confirmed that the council were considering having the child removed but as circumstances had changed at home – the decision to proceed was currently on hold. In that meeting we observed one social Worker to be very aggressive and confrontational towards Mum.

When we stated why we were now involved with this family the tone of the meeting changed. We had asked a number of questions, such as:

- a) The council were aware that this child had an acquired brain injury? NO
- b) Is the child under the care of the Children with Disabilities Team? NO. They refused the referral because the child does not have a disability.
- c). Has Mum had a Carers Assessment? NO
- d) Is Mum receiving any Carers Benefits? NO

The council eventually acknowledged that this family had indeed been through a traumatic ordeal and they now accepted the child has sustained a serious brain injury. However, because of personal prejudice from several Social Workers, it was felt the family had not received fair treatment. It was stated that, "when this desperate mother was appealing to us for help; we had turned and attacked her and beaten her with sticks"!

Working alongside the council staff, we were eventually able to have this child referred to the Children with Disabilities Team.

This traumatised mother had been treated appallingly. She had a serious mental health condition and had simply been 'left to get on with it.' She had no family support or access to any other emotional, psychological or social support. To add to an already stressful situation, Social Workers and Child Protection Services, and the child's school were all punishing and blaming this mother for the aggressive behaviours of the child.

Child Protection Professionals

Despite a range of Child Protection Professionals being involved with this family; the traumatic experience Mum had suffered; and the significant brain injuries the child had sustained; none of these issues were taken into account. Mum was not listened to and a brain injured child's needs were ignored for almost two years.

We were asked to submit a report for a Child Protection Review Conference. The Chair reversed Social Services decision to have the child removed. They also requested that we submit a copy of our report, alongside a formal complaint to the Director of Children's Services.

Education

The child was not meeting the expected development milestones and was behind at school. This was also confirmed in their end of year school report. Concerns had also been raised about the child's ongoing development by the nursery. Despite Mum telling the school about the child's brain injury, the school did not deal with anything and this child's complex needs were not being met or supported. As such this child ended their first year at school significantly behind their peers.

School staff were also very prejudiced towards Mum, due to the family background, which also negatively influenced the Child Protection proceedings.

Although Mum was mentally ill, she had consistently tried to fight for the needs of her child; but had been failed at every turn by statutory bodies. However, the person the suffered the most was a vulnerable brain injured young child whose complex needs were ignored and remained unmet for two years by every adult within multiple statutory agencies that were involved in the case.

We understand a serious case review took place.

Case Study 4 - D

D is a 13 and was referred to us by an Early Help Team. The child is now involved with local Police and the local Youth Offending due to the anti-social behaviour being demonstrated.

The child was born healthy, following a normal delivery and without any complications. They hit all their early expected development milestones and Mum says they talked and were potty trained before the age of one. Despite being involved with CAHMS for many years nothing had improved for this child.

This child is very bright and excels at maths and activities that play to his exceptional practical skills. i.e. building flat pack furniture; car mechanics etc.

It has transpired that the individual had sustained a head injury when he was a baby which caused a seizure and a hospital admission. At that point, the family were referred to us by the local authority early help team. We learned that the child had actually incurred three separate head injuries before the age of 8. Unfortunately, as each injury was dealt with in isolation at the hospital, any potential damage caused to their developing brain by previous head injuries have not been considered in this child's ongoing development.

Approximately two years ago, D started to demonstrate completely changed behaviours. Since then they are becoming increasingly anti-social and aggressive and issues are escalating in nature and seriousness. The child has no emotional responses, fears nothing and lacks understanding of their actions, consequences and reactions by others.

In the last 12 months, D has been excluded from four secondary schools and a behavioural assessment unit. They are now being temporarily home schooled. They have no good friends and is socially excluded. Mum says the child is asking his mother to please get the child some help.

We discussed the three childhood head injuries with Mum and completed our own brain injury assessment. We then discussed the results with a Paediatric Consultant. This child is demonstrating significant problems in the areas of communication, cognition and 'behavioural and emotional'. They also have substantial problems with fatigue, pain and sleep, which are increasing the risk factors surrounding the child's quality of life, academic learning, actions and behaviour. We have also learned that the child also has significant memory problems and has a short attention span.

Concerns about the child's mental capacity and treatment are also emerging when being questioned by personnel from statutory bodies. There is also a consensus by a range of community professionals involved with the family, that the child is vulnerable and at risk of exploitation by others due to his cognitive problems.

Even more concerning is this child was left in an extremely vulnerable position when they were dropped off miles away from home late at night by Police Officers after the child was released from police custody. Mum was not informed and the child had to make their way home alone.

To date no formal acquired brain injury diagnosis has been made; nor has the child received an MRI brain scan. This child is not currently under the care of any medical professionals, other than his GP. We understand they were referred to CAHMS but they were not able to help. Mum states the child has never been referred to a Paediatric Consultant who specialises in acquired brain injury; nor has the child ever been assessed by a Paediatric Neuropsychologist.

Health

We discussed the outcome of our brain injury assessment with a Paediatrician who agreed it is highly likely this child has an acquired brain injury. We wrote a letter for Mum to provide an overview of this child's case which the Consultant requested. Mum has taken this to their GP to ask for a referral to a named Paediatric Consultant in James Cook Hospital. This child has now been seen by an appropriately experienced Consultant.

Criminal Justice

We attended an MDT meeting at a behavioural assessment unit with Mum and Dad. Present were representatives of a number of agencies. The purpose was to discuss the child's behavioural issues and to exclude the child from the behavioural assessment centre. We discussed the findings of our brain injury assessment and we raised concerns about mental capacity issues for the child. We agreed to ensure the child was referred for a formal medical diagnosis to a specialist paediatric Consultant. (See above).

Education

In the absence of a Nurture Room within the centre; it was suggested that the child be home schooled on the interim until an alternative school could be sought that would meet his emerging special needs. Recent feedback from the family is that child is working well at home with a personal tutor; they are completing all their school work; and homework is being completed and produced to a high standard. The child is even doing more work than was requested!

Family Support

The family are also now receiving regular emotional and practical support from us. Mum is being offered Holistic therapies to help with stress relief. We continue to support this family and provide advocacy support for the child.

Case Study 5 - E

E is 11. The family self-referred to us for help with their child.

When we met with Mum she was able to provide detailed information about the child's brain injury, the cause and how it has affected the child. She also had scan photographs which confirmed the severity of the child's brain injury. As a result of the illness that had occurred, part of the child's brain had not grown and developed properly. The child is in receipt of DLA. A severe brain injury had also been diagnosed by his Consultant.

We learned that E had bacterial meningitis as a baby which had caused a non-traumatic brain injury. Two separate medical reports had confirmed E had severe brain damage. Mum also provided us with all the medical and other reports that had been completed for the child. She was concerned about her child's changing behaviour and frequent fighting, and the family are now involved with the councils Early Help Team. She isn't coping and her strategies aren't working. The child's aggression is escalating.

The child has recently moved up to secondary school and problems are emerging with disruptive behaviour in class and fighting. Mum is also concerned that it is not the correct school for the child. E had spent the whole of their primary years in a specialist unit but was now expected to fit into mainstream school and the busy secondary school environment. The child's behaviour is also having a

significant negative impact on the family's quality of life and is particularly affecting the other children living in the house.

We completed a brain injury assessment with her to determine how the brain injury mapped out against the known deficits of ABI and the impact it was having on the child's life. It showed the child has significant communication, cognitive and emotional and behavioural issues. Other problems included increased sensory problems; risk-taking behaviours; sleeping problems; fatigue and concerns about pain. The child does not feel pain. Although Mum was aware of some issues- she was not aware of the levels, significance and complexity of the child's problems and what that means for the child. Our service has helped her to understand that.

Health

We understand the child is currently under the care of a paediatric consultant in James Cook. We have produced a report and the child is still waiting to be seen by a paediatric Consultant that will outline the emerging problems and risks. We feel they may be far greater than the Consultant is currently aware of.

School

We attended a meeting to discuss the child's poor behaviour and find a solution. The child was very disruptive in class and had frequent detentions. They were also frequently punished for not being organised and forgetting things.

It became clear that the school were not aware of the child's brain injury and the issues that are affecting the child's behaviour. Despite the child being in a specialist centre, their file had not been sent to the new school so even the SENCO was unaware of the child's needs. We shared the results of the brain injury assessment with the school and the staff were shocked at the level of needs the child had.

Despite this child being in a specialist unit for 6 years; and missing all the expected development milestones, they did not have a SEN statement or an EHC Plan. The last Educational Psychologists report was completed over 6 years ago; indicating significant failures by the primary school. Mum said the school had said another assessment wasn't necessary as they had decided that the child was ok so hadn't requested another one!

With the information we provided, the SENCO does not feel that this school is right for the child as they cannot provide for his specialist needs. She stated it will take up to a year to have the child's needs assessed to enable them to move to another more suitable school. The child will therefore need to be uprooted again and taken away from friends and start all over again. This will likely have a significant effect on his behaviour again.

At the meeting, we suggested that the child be taught in a smaller group and recommended they be placed in the Nurture Room. The school agreed to try this.

We met with the school again two weeks later. The child is now in the Nurture Group with one-to-one support. The school agree this setting is more suitable for the child and better meets their identified brain injury needs. However; this is only a short-term solution and the child will need to be transferred to another school that can meet his special needs. The child sees friends at break-times and lunchtimes. An Education Psychologist Assessment had been requested and we pointed out that they needed to understand the complex effects of acquired brain injury to be able to effectively help this child. We

offered to assist if it was felt necessary. Another meeting was set for four weeks' time – which we will attend with Mum.

The relationship between school staff and the child continued to deteriorate and following an incident at the school, and Mum spending an evening in A&E, Mum eventually withdrew the child citing her child's wellbeing and safety as being more important.

Social Care

Despite the child being awarded DLA, the family do not have a social worker and child is not under the care of the Children with Disabilities Team. His neurological disability and associated impairments remain unacknowledged. Mum was not aware of her entitlement to a Carers Assessment and has not had a Carers Assessment completed. Nor is she aware as to whether the child is on the council Register of Disabled Children. Despite Mum being a single parent, the family do not have access to Carers breaks or any other support that she should be entitled to. This would also make a massive difference to both the child and the family.

Outcome:

This child now has an EHC Plan that includes the finding of our brain injury assessment has an EHC Plan. This is the first time their complex needs have been properly identified and acknowledged. They have also moved schools and to date the child remains settled in the new school.

Case Study 6 – F

F is two years old. The child sustained a devastating brain injury aged 1, which has left them with significant disabilities and complex needs. The family were referred to us by hospital staff. We have been supporting this family for 2 years.

During this time the involvement we have had with this family has potentially helped to minimise other potential risks for this child.

The child had sustained a severe non-traumatic brain injury as the result of a sudden onset illness. They spent several weeks in a coma in Paediatric Intensive Care. Although Mum and Dad were relieved that the child had survived -it was bitter sweet because their child is now severely disabled.

Hospital Meetings

Mum and Dad asked us to support them at several MDT meetings in the hospital and including the Discharge Planning Meeting.

During the Discharge Planning Meeting, we suggested that as the child was now visually impaired, the parents purchase some sunglasses to try to protect the eyes from any further potential UV harm as they were no longer reacting to bright light. This was also important as post brain injury people can experience increased sensitivity to light. The Consultant agreed with this recommendation.

We also asked about the appropriateness of the child's car seat. It was stated that the car seat had been assessed by the Road Safety Team and had been deemed safe for the child's age and weight. We expressed concern that it may no longer be safe for a brain injured child that was now severely disabled

with no head control and unable to self-mobilise. Another professional agreed to check this at the pre-discharge home visit. When assessed for the now changed needs of the child – it was found the car seat was not suitable.

We researched potentially suitable car seats and we worked with Dad and the OT to find a suitable and safe replacement. We also ensured the OT approved the car seat before it was purchased. However, the cost meant the family could not afford to buy in at such short notice. Out of the project budget we bought the car seat for the family – without which the F could not have been discharged from hospital.

At home, the family had to adjust to a significantly different way of life. The child they had known was no longer there. Both parents were completely devastated and physically and emotionally exhausted but they said they coped because we were there to help them and support them. During the early days we visited them four times per week to provide emotional support and practical help.

The child now needed to regularly take a significant amount of medication that was administered both day and night. F was also NG tube fed but had problems feeding and was persistently vomiting which was really upsetting Mum and was adding to parental stress and anxiety. This continued for weeks!

F was also at significant risk of inhaling vomit – which had happened several times in hospital – and had caused lung/chest infections. Also, when F vomited, the NG feeding tube became displaced and this needed to be reinserted by the community nurses. Mum was also concerned that not once was the child's chest checked to ensure vomit had not been inhaled or checked for any potential infection.

Whilst all this was going on - we also experienced some very hot weather. We became increasingly concerned that despite a range of professionals visiting the child every day, nobody appeared to be concerned that his child was regularly vomiting his full feeds.

The level of daily vomiting meant the child:

- a) was not receiving the nutrition he needed to keep him well;
- b) the lack of food being absorbed could also have significant implications for how much medication they should have been given – even though Mum was correctly following the plan given by the hospital;
- c) the hot weather also meant that there was an increased risk of this vulnerable child becoming dangerously dehydrated.

In the interim to record this we contacted the dietician to express our concerns. We also created a vomiting chart that Mum used to record the time and how much the child was vomiting.

Day-to-day a range of NHS community professionals were visiting the child at home but as this went on for weeks - this meant that Mum could not leave the house at all. This was also adding to her stress levels and was affecting her mental health wellbeing. Dad works permanent nights - so slept during the day. Mum does not drive so could not have any time away from the child or the house.

With so much pressure on Mum, her wellbeing started to suffer. We could see that she needed a break – but with so many appointments for the child - it was impossible. Mum had become a prisoner in her own home. We asked the professionals to also consider Mums needs and asked if they could align their visits so that Mum had the opportunity to have a break and go out with us.

The GP didn't visit to see how the family were coping. Both parents knew very little about their child's brain injury and had been provided with very little information. We provided the information they needed to help them to understand.

Social Care - Children with Disabilities Team

F had been appointed a Sensory Loss Social Worker from the above team. The Social Worker also worked closely with a professional from Continuing Healthcare Team. We learned that the role of both professionals was to assess need and make recommendations to a Panel to commission care services for the child. They told us neither knew anything about acquired brain injury and its complex effects.

The MDT meetings had no terms of reference – so parents were unclear as to the purpose of the meetings and what should have been discussed. Shockingly every detail of this family's life was discussed openly with everyone present. Mum withdrew from the meetings and would not participate preferring to stay at home with F. During these meetings, there were times when what was being discussed was humiliating for Dad. The professionals present, did not pick up on this.

Parents were also asked to make important decisions for their child's needs with no prior warning that this was to be discussed. Nothing should be discussed at a meeting without the parents knowing in advance and giving their permission for this to be discussed. Whilst we acknowledge that the disabled child needs to be appropriately safeguarded; this does not mean that statutory bodies can trample all over every aspect of their lives.

Every aspect of this family's private life was discussed in front of every professional who attended - and whoever else was shadowing them that day! These meetings should have been planned so that issues were discussed only with those who needed to know. At times Dad felt very uncomfortable, disinterested and emotionally detached from the whole process. When he was unable to make an informed decision, he just agreed with whatever was being suggested – whether it was right for his child or not.

Although we acknowledge that a vulnerable child needs to be appropriately safeguarded – in the community MDT meetings, consideration should also be given to the human rights of the parents for 'a private and family life'. Parents should be provided with the Terms of Reference so they know the purpose of the meeting. They should also be provided with an Agenda before the meeting so they know what will be discussed about them and who will be present. Not every community professional should know everything! Parents should be informed in advance of any decision that needs to be taken – giving them time to fully discuss those issues in private. They should also be provided with enough information to make an informed decision – rather than be put on the spot and expected to make an immediate decision.

This is also where parents need to be better informed about their child's brain injury, prior to discharge. How can parents make informed decisions at these meetings – when they don't understand what has happened inside their child's head?

How can they keep their child safe – when they don't know what the potential risks are?

How can a hospital Consultant effectively manage the complex needs of a brain injured child living at home – when they do not see them regularly - and the community professionals are not alerted to serious threats and risks that should be reported back to the consultant?

The treatment this family received from a range of professionals from different agencies involved in the case, significantly exacerbated family stress and pressure within the family unit which was completely unnecessary. The needs of this child are changing constantly and F has required further surgery. We continue to support this family and will do so for some time to come.

8.0 OUTPUTS

8.1 In the funding application we also said we would deliver the following:.

Families

- Improve family relationships in 20 families
- Reduce/improved mental health issues for 30 parent carers
- Improve personal health and wellbeing for 30 parent carers

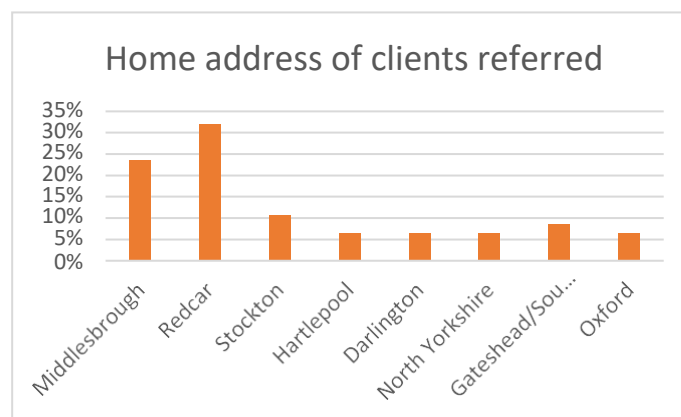
Children and Young People

Improved outcomes for children and young people recovering from acquired brain injuries

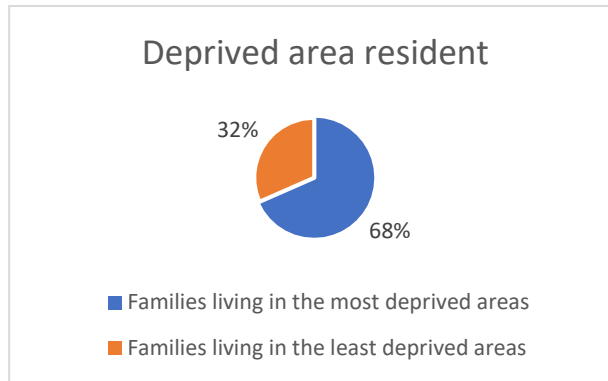
8.2 To date we have supported 55 people that have been affected by acquired brain injury. These were either children, young people or their parents. Every child's case is unique and the needs of their families are both complex and diverse. Working with these families is very time consuming.

8.3 The project initially got off to a slow start but now we are up and running and as other services become more aware of us we are receiving more referrals. We are also starting to receive referrals from Darlington, Stockton and Hartlepool. A shortage of funding and limited staff resources is now constraining how quickly we can reach all of these families.

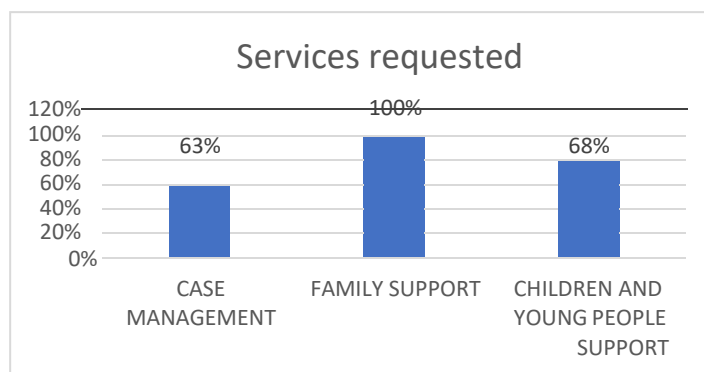
8.4 55% of all our referrals have lived in Middlesbrough, Redcar and East Cleveland as this was where we prioritised the promotion of the project. The remaining 30% were from across the Tees Valley area and North Yorkshire with approximately 15% from Oxfordshire, South Shields and Gateshead. A further breakdown is shown in the table below.



8.5 At the point of writing this report, 68% of the people we have supported to date live in deprived areas; meaning these children are predicted to have poorer outcomes post brain injury and are likely to suffer more than one brain injury.



8.6 All of the Families requested Family Support (but many also requested help and support for their children) and Case Management work either for their child or to help with other problems the family were experiencing. The percentages are shown in the chart below.



8.7 Some of the other issues we have supported brain injury families with through our Case Management work were that were external to this project included:

- Housing
- Debt
- Domestic Violence
- Immigration issues
- Benefits applications
- Benefits appeals
- Youth offending
- Education issues
- Child protection issues
- Transport
- Legal issues

8.8 Our involvement in these issues was important as other agencies have been unable to explain acquired brain injury and its impacts on the child/family; or have been unable to advocate for the needs of the child or their family due to a lack of awareness and understanding.

8.9 We are also pleased to report that during the lifetime of this project we have made some efficiency savings by finding alternative ways to successfully deliver the project. This has proved to deliver better value for money without diminishing the quality of service we provide.

8.10 We have also collected a lot of data which is collated and compiled into an evidence and data report that is updated quarterly. This includes quantitative information on the families including: where the referral originated from, reason for referral, where the family lives, deprivation, ages, ethnicity, sibling information and also qualitative data such as wellbeing scores, feedback on the experience of receiving our services, and data on service provision such as number of visits, hours of support provided and the issues that were being experienced by the families. The data is evidence we use to report on the effectiveness of our service, the direct experience of the families and the cost effectiveness.

9.0 OUTCOMES

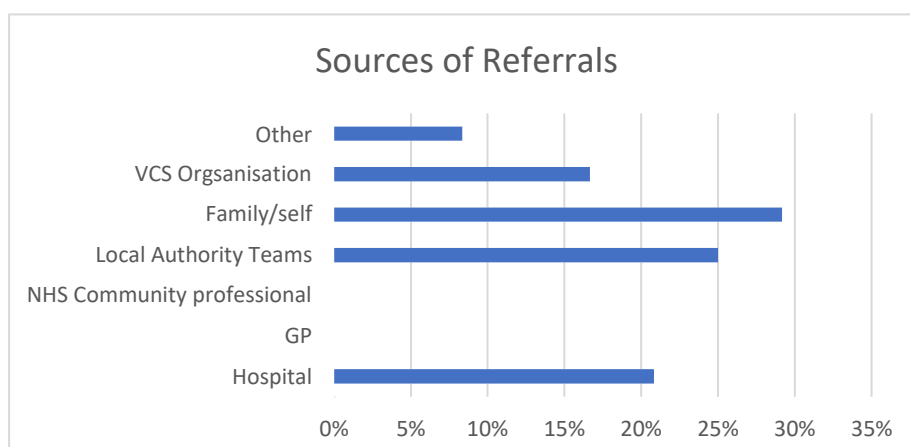
Where did our referrals come from?

9.1 Initially, the largest proportion of referrals came from **families** themselves; followed by either **James Cook Hospital** or other **Voluntary Community organisations**. More recently they are coming from local authority early Help Teams or other disability services as they become more aware of Matrix and our services. In response, we are now seeing an increase in the numbers of referrals.

9.2 Unfortunately, we did not receive any referrals from GP's. However, when we ask parents how much their GP understands brain injury; they say very little. They also say that GP's tend to refer these children to CAHMS; whether it is appropriate or not. We think this may be due to a lack of understanding of the deficits of acquired brain injury and the complex effects that impact on child development, health and wellbeing.

9.3 Interestingly, we did not receive any referrals from NHS Community professionals despite them being made aware of our services.

9.4 Sources of referrals:



9.5 As described in the initial funding application we have developed a range of self-assessment questionnaires that parents complete at specific periods in time. These cover Family Relationships; Personal Health; and Personal Resilience. A baseline assessment is undertaken as soon as possible and comparisons are made on an ongoing basis. We have also developed an outcomes wheel to compare before and after results. This data can also be presented using comparative scores. Using this information, we can report on the effectiveness of our service.

9.6 Notably, as shown in the table below, from their initial baseline scores the biggest areas we have improved or maintained are in Family Relationships and Personal Resilience. If this is related to the known impacts on the family (as stated in 3.23) it is clear we are starting to make a positive impact on families; despite some other significant issues they have faced.

9.7 Our services also aim to improve the health and wellbeing of parent carers. The same five families were selected as both for the before and after scores. During the period that we have supported them, some have also faced additional adversity for a range of different factors.

- 9.8 When reflecting on
- the Case Studies
 - considering what the families of brain injured children are dealing with on a day-to-day basis; and
 - how they tell us they feel they are treated by statutory bodies

Wherever we have maintained a score through any additional adversity they have faced, it should also be considered a positive outcome.

9.11

FAM	NEW PARENT CARERS BASELINE SCORES			PARENT CARERS LATEST SCORES			OTHER NEGATIVE
	Health	Resilience	Family	Health	Resilience	Family	FACTORS THAT HAVE OCCURED
	Max score 10	Max score 10	Max score 10	Max score 10	Max score 10	Max score 10	
1	3.73	3	7.75	3.65	5.29	7.67	PTSD DIAGNOSIS
2	4.69	6.14	7	6.96	6.79	7.17	BEREAVEMENT
3	5.73	1	9	5.54	6.71	9	
4	3.92	3.58	3.92	4.92	5.5	4.8	
5	6.29	5	9	5.73	6.86	9	

9.9 Our services have helped to improve family resilience and interpersonal relationships within the family. We help to create a more positive and healing/rehabilitative atmosphere so parents can cope with ongoing changes that will likely continue to emerge over time.

9.10 We set four aims for this project – as outlined in bold below – and we are pleased to state that we have achieved Aims 1, 2 and 4. For each Aim, we have provided more detail to justify how this has been achieved.

Aim 1

The creation of an effective new community based service aimed at supporting parent carers with a view to improving mental health and building family resilience to cope with the impacts of acquired brain injury in children and young people.

9.11 Our project has been successfully implemented within the given timescale and has become a valued service not only for child brain injury families, but also other health and community professionals as reflected by the growing number of referrals we are now receiving.

Aim 2

Improved mental health issues in parent carers;

9.12 We have demonstrated the difference we have made to parents through our Family Support Work as shown at paragraph 7.12 and 8.3. When we first meet families, they are all in a desperate state with many demonstrating severe anxiety and emotional distress. Our service has been successful in supporting families dealing with the effects of a young person with acquired brain injury. We have been effective by working to ensure that the whole family is supported in whatever way they need to ensure that they are all able to participate successfully in their community, achieve the best health outcomes which are possible for them, access information, training and education and individually and collectively maintain their overall health and wellbeing.

9.13 When we analysed the feedback from parents and carers the trends were as follows:

MENTAL & PHYSICAL HEALTH	↑
PERSONAL RESILIENCE	↑
FAMILY RELATIONSHIPS	↑

9.14 To demonstrate how we did this, we thought it would be useful for you to hear some of the comments parents have made regarding this project.

PARENT COMMENTS

“I really felt listened to and you cannot know just how important that is to me. I’m sure you recall just how frustrated I have felt in living through this experience. It was so unnecessary.” LN

“Thank you for your valuable help. You have been very kind and have put us in touch with the right people. You do wonderful work for head injured people and you understand them.” WKJ

“We appreciate your input into our lives. Now things are slowly turning around for us”. VK

“It is a refreshing change to speak to someone who actually ‘gets it’ and knows what I am talking about. We have been left in limbo and despair for many years. I cannot explain the massive difference you have made.” DA

“We are so happy to have found this service. We are getting so much more help and support – more than we have had in years.” RG

“The therapies you provide are really beneficial and I now get time to relax which is really helping me.” SC

“We can’t believe the amount of work you have done for us. We appreciate it all”. Anon

“Thank you for giving up your time today. God knows how we could have got through this without the support of Matrix. We would be lost without your help and support. It finally feels like we are on the right track. We cannot thank you enough. WJ

Aim 3

Provision of a coordinated approach to support faster and improved hospital discharge for children, young people and their families who are now coping with a ‘different’ child. (A child living with neurological disabilities and acquired special needs)

- 9.15** From the feedback we have received from families our project has made a difference to them by:
- facilitating access to joined-up services through our Case Management Work and
 - by providing advocacy, information to increase knowledge and understanding, advice, and support. This has meant there is less stress and emotional hardship within the family as they know that their child is getting the best help possible.
- 9.16** Through our self-assessment forms Parents have told us that their family resilience and interpersonal relationships have improved and there is a more healing/rehabilitative atmosphere and with our support, improved ability to cope with ongoing changes that will likely continue to emerge over time.
- 9.17** It is also important to note that Toxic Stress in the latest term being used to describe the main factors within ‘troubled families’. Poor child behaviours related to brain injury is not as the direct result of toxic stress; although when parents are struggling to cope there may be an element of this. There is a real danger that in brain injury families, parents will be ‘labelled’ under this banner. Toxic stress within brain injury families may be another ‘symptom’ of a child’s brain injury that the family are struggling to cope with. In these circumstances focussing purely on a ‘Toxic Stress’ atmosphere will NOT solve the problem for these families.
- 9.18** When we ask our parents’ what will make the biggest difference to your life? They say “help my child; because nobody else does. They just don’t understand.” In child brain injury families, the only way to engender change within the ‘troubled’ family unit, is to provide effect solutions tailored to the complex rehabilitative needs of the brain injured child. This will not happen if the child’s needs are not understood in the first place.

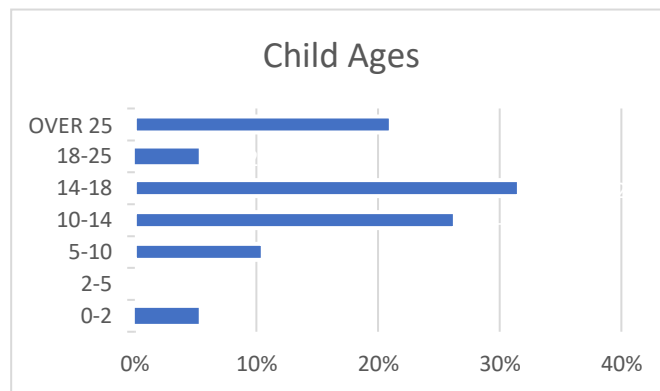
Aim 4

Provision of long-term support for families of children and young people who are now living with a life-changing long-term condition.

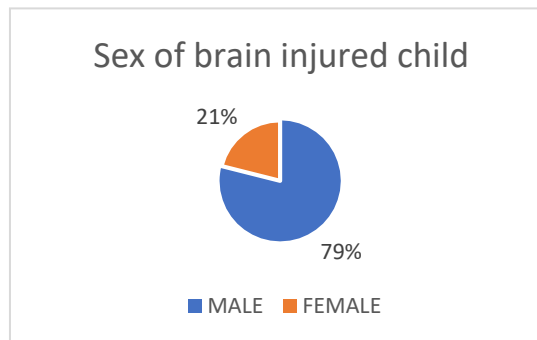
9.19 Our services are also making a direct difference to the children receiving care, as, they get better, more regular and tailored support that is tailored to their needs. However, there is much more that Matrix can do to help improve their ongoing recovery and improved neurological functioning. We will be seeking additional funding to roll out more support services particularly for those children and young people who are socially excluded; are struggling with their recovery; where the brain injury has impacted on their ongoing development and neurological functioning.

10.0 STATISTICS AND DATA

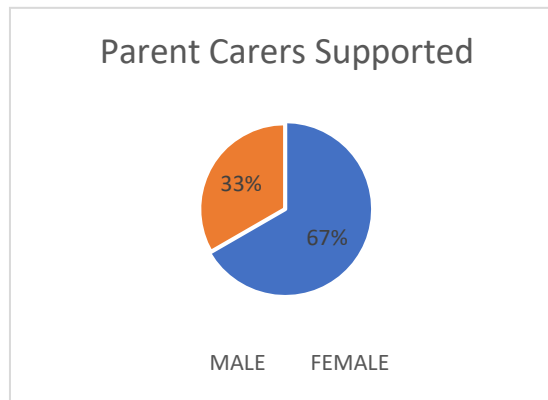
10.1 The ages of the children and young people we have assisted were:



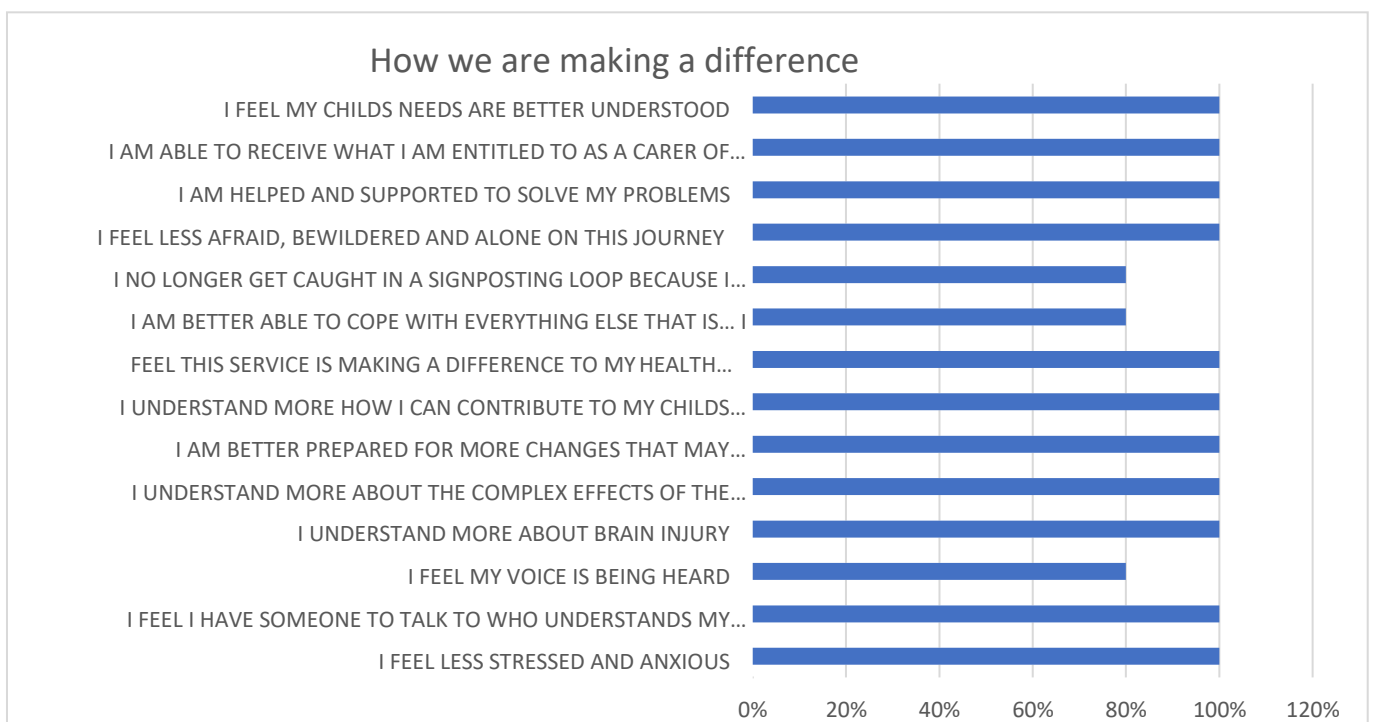
10.2 Of all the children and young we have helped 79% were male and 21% were female.



10.3 Of all the parent carers we supported 33% were male and 67% were female. We found that it is generally the females that tend to take on the main caring responsibilities for the brain injured child. Many are unable to work because they are frequently called to school to deal with the behaviours of their child; whose acquired learning disabilities arising from their brain injury are not recognised or supported by the school in the first place. Parents are therefore constantly on stand-by. When these children are excluded from school; they are unable to work because they need to stay home to care for their child. However, it seems all parents with caring responsibilities for brain injured children are unrecognised and unsupported and the majority do not receive any carers benefits.



10.4 Matrix set out to make a real difference to families so we asked or families to tell us if we were. We received some very positive feedback, as shown in the following chart. They said:



10.5 Case Management Service

The need for a Case Management service emerged very early. There are two aspects to Case Management that have emerged. Type A is for the child. Type B is for the family.

Type A

Families had so little information, awareness and understanding of acquired brain injury they were unable to advocate for and explain to other people, the complex needs of their own child. Parents were then not listened to and frequently told “there is nothing wrong with them” by unknowledgeable professionals. Also, whilst they aware of the current symptoms the child was portraying now; they were unaware of other factors that may be contributing to those factors; they lacked awareness of existing risks to their child; and did not know about other potential issues that may yet emerge as the child grew and developed. This is important information that they need to know and was the reason for creating the brain injury assessment tool. All our Case Management work was done on a voluntary basis by our Chair. As a result, families now have an increased understanding of all the factors

pertaining to their child's brain injury. Our Case Management work not only helps the child; it also supports the parents by helping them to solve a range of other issues affecting the family. More information is provided at 8.7 in this report.

Type B

This is more related to the problems the parents are having which is also impacting upon family anxiety and pressure. Where parents have limited emotional resources themselves, it makes it harder to deal with their own responsibilities and to solve their own problems; which then exacerbates stress further. Through this type of Case Management, the issues we have supported parents with, or helped them to access professional services include:

- Housing
- Debt
- Domestic Violence
- Immigration issues
- Benefits applications
- Benefits appeals
- Youth offending
- Education issues
- Child protection issues
- Transport
- Legal issues

10.6 There is also a lack of relative and appropriate educational material available to parents. We say appropriate because most of the other charities provide leaflets and other generic information that have been written by academics, and are too 'wordy' and lengthy for parents; so, parents find them unhelpful. Parents want to know about their child and their child's brain injury; not what might be. They do not want to know how a brain injury affects somebody else's child or receive generic information that does not directly affect their child.

10.7 Through our Founders lived experience and by talking to parents we have determined what parents both want and need and in what format. We appreciate they have very little free time to read lengthy leaflets, book or other documents so we produce what is appropriate for their needs. Our animated DVD is five minutes long and tells parents and children everything they need to know, simply, clearly and succinctly.

10.8 Brain injury assessment tool

Any brain injury is complex, but to a child's developing brain it creates wide-ranging deficits as agreed by the Royal Society of Rehabilitation Medicine and the Royal College of Surgeons. Parents are not provided with this information at all so to help raise awareness and help parents to understand their child's brain injury, we created an assessment tool that explores all the child's post-injury abilities.

This tool also considers a range of other important issues that may have been missed by medical professionals. To date this tool has highlighted a range of issues and medical problems that children are living with, but not being treated for. This may also be due to the parent not knowing because the child has not said anything; or because the parent didn't know it related to the brain injury.

10.9 Brain Diagrams

It is crucial that parents to understand the wider impacts the initial brain injury can have on the child. Children are so often diagnosed with a frontal lobe injury by consultants; when the impacts and deficits of that injury are wide ranging and may be significantly affecting other areas of brain function. We use a range of information to build a profile of the child. The more information parents have; the more they understand. With our help, parents are supported and can be provided with appropriate activities and strategies that will help their child.

11.0 CONCLUSIONS

11.1 MATRIX Neurological is truly an **innovative** children’s charity, established to provide practical help and support to children, young people and their families who are living with the effects of an acquired brain injury. The founder of Matrix created the organisation because of first-hand experience of child brain injury and the lack of appropriate help and support that brain injury families need. In 2010 her son sustained a severe brain injury.

11.2 Our Mission is:

“To work to remove inequalities for children and young people affected by acquired brain injury; and provide effective support to their families that make a real difference.” The Family Support Project and this project report has contributed towards that Mission; but there is still a long way to go.

Incidence of acquired brain injury in children and young people.

11.3 It is widely acknowledged that acquired brain injury is the biggest cause of death and disability in children and young people. The incidence of paediatric traumatic brain injury alone exceeds all other neurological disabilities as shown in the table below. A study was completed by McKinley et al, 2008; McGuire et al, 1998. A report entitled, “**Nobody made the connection**” was produced for the Children’s Commissioner in October 2012 and states:

The reported prevalence rates amongst young people in the UK population per disorder are:

Autism	0.6-1.2%
Learning Disability	2-4%
ADHD	1.7 – 9%
Dyslexia	10%
Traumatic Brain Injury	24-31.6%

The Children’s Commissioner is now calling for better treatment for children and young people who are living with an acquired brain injury.

Discrimination faced by brain injured children and their families

11.4 Throughout this report we have highlighted how brain injured children, young people and their families face discrimination everyday due to a lack of understanding by staff across a range of statutory bodies whose role should be to help and support them. This cannot continue and public bodies must accept acquired brain injury as a recognised disability in children and find a way to provide for the needs of these families accordingly; across all aspects of health, education and social care. Only then will children and young people achieve better outcomes. When brain injured children are refused Education Health and Care Plans – unless the child had sustained a physical disability or has sensory loss - then they are being prevented from ever achieving a good long-term

outcome. These children need help and support not exclusion and punishment. Their parents should also be receiving Carers Assessments and Carers Benefits for the significant caring role they undertake and the acknowledged importance in helping to deliver good outcomes for their child.

System failure

- 11.5** Based on the reported incidence of traumatic brain injury as highlighted in the 'Nobody made the connection' report; and the ONS child population statistics for the Tees Valley that indicates there may be 50,844 children and young people living in the Tees Valley whose complex needs are not being met. High levels of deprivation and poverty will also have a significant impact on the numbers of children living with the effects of an undiagnosed TBI. This is both unacceptable and discriminatory. All agencies need to come together to address this significant issue. Matrix is in an ideal place to make a significant contribution towards reversing this trend.

Lack of tailored neuro-rehabilitation provision and support for children and young people

Probably the most significant factor that is not acknowledged across all multi-agency professionals, is the child's potential for regaining lost skills and abilities post brain injury with appropriate levels of support. However this is much broader than the usual physiotherapy and Occupational therapy. Old school thinking by medical professionals thought that as children's brains were still developing and by being in the school environment, children would naturally regain lost skills and abilities. They now know this to be untrue; and agree that children need a level of support tailored to their individual needs and neurological deficits to maximise their potential. Unfortunately, this does not happen across any sector. Parents also play a key role in facilitating good outcome post brain injury; however, they are not provided with the information and tools they need to achieve this. Matrix provides an exciting opportunity for the Tees Valley to show some national leadership and work to improve service provision for brain injured children and young people.

Impact on families

- 11.6** Research shows that ABI has a significant psychological impact on families; which result in a range of problems and poor outcome for a child or young person. The need for the project originated directly from service user experience, has been confirmed by regional specialists and our previous project beneficiaries, and reaffirmed by national and regional research. This is now also being confirmed by the number of referrals we are receiving.

Improved wellbeing

- 11.7** Brain injury families suffer discrimination and other mental health issues, unnecessarily. As one Case Study showed, parents are 'beaten by sticks' by the organisations that are supposed to be there to help them. Ultimately our project aimed to improve family wellbeing and resilience and improve the rehabilitation process for the child. We are now starting to address poor health and developmental outcomes in children and improve mental health in parent carers. These problems particularly affect people from disadvantaged areas as they experience higher risk and incidence of brain injury and demonstrate poorer rehabilitation outcomes (Lequerica and Krch, 2014). **The results from our parent self-assessment forms show we are doing that; but much still needs to be done to support parents and achieve improved outcomes for brain injured children.**

Need for our services

11.8 We have continued to consult with families, Consultants and nursing staff and all agree there is a huge need for our services. Some families have stated that for the first time in 11 years we are being supported by people who understand. Families confirm this in their statements shown in section 9.18 and 10.4. Also, paediatric consultants and nurses have stated need as being:

NEED for MATRIX	
FAMILY SUPPORT SERVICE	HIGH/V HIGH
CASE MANAGEMENT SERVICE	HIGH/V HIGH
SERVICE NAVIGATION	HIGH/V HIGH

We know that NHS Consultants want to see better outcomes for children and young people post discharge too.

11.9 We have always said that the NHS and other public, private and third sector organisations do not meet **all** the needs of a brain injured child and that good neuro-rehabilitation provision is much more than is currently provided by any sector. If what was currently being provided was fit-for-purpose, families wouldn't be left in the position they are; so many young people would not be incarcerated; and children would be achieving better outcomes post discharge. To deliver improved outcomes for children and young people, it is essential that neuro-rehabilitation services:

- that the effects of an acquired brain injury are properly understood
- are designed by children, young people and their families; not professionals
- consider ALL the needs of both the child and the wider family
- add significant value to existing NHS services
- provide a baseline assessment through which to monitor changes in children and young people; which may not otherwise be identified, supported and acted upon
- help to create better long-term outcomes for brain injured children; not just treat the current symptoms
- ensure children and young people are referred back into NHS services to receive treatment for any new/missed or emerging medical issue where appropriate
- help minimise unnecessary stress and parental burden by keeping parent carers both educated and well through well-designed services based on a sound understanding of their needs and less judgemental views.

11.7 Consultants are also telling us that our brain injury assessment tool provides a helpful overview of the needs of the child which then enables them to get the best out of medical appointments; target interventions; prescribe medication; or refer children on to other services in James Cook Hospital. i.e. Ophthalmology; Audiology etc; thus, making a real difference to the lives of brain injured children.

Criminal Justice

11.8 The study undertaken by NHS Scotland and the Scottish Prison Services highlights the prevalence of traumatic brain injury within the prison population. Case Study 4 highlights how improved understanding of a child's needs and with the right help and support, children may respond better. If the child is engaged and stimulated in a way that is tailored to their individual needs, it may also steer the child away from criminal activity. If we stop punishing brain injured children for a hidden disability that they (and their parents) often can't explain, and provide tailored help and support to help them achieve; it may channel the child's frustrations into more productive activities that may lead to

improved outcomes and a meaningful contribution to society as opposed to frequent contact with the criminal justicesystem.

Schools

- 11.9 Brain injured children and young people often struggle in schools due to a lack of understanding by teachers and support staff of their complex needs as well as associated risks related to neurological deficits. These children also often have undiagnosed sensory needs which inhibits their ability to filter out other distractions which then impacts upon concentration and other skills needed for learning. Creating the right environment for a brain injured child to learn is key to minimising the risk of behaviour issues and emotional outbursts. Nurture rooms appear to work with this cohort. They have small student numbers; and 1-1 or 1-2 SEN support seems to work well.
- 11.10 If Nurture Rooms were made available for brain injured children regardless of their age, they may be able to stay in mainstream schools and achieve academically. Professionals need to look at the emerging issues from the child's perspective rather try to fit square pegs into round holes and ignore the complex needs of these children.
- 11.11 There are three important factors that influence a child's successful integration/reintegration into school post brain injury. One is understanding what has happened inside the child's head; second is what has changed; and third is understanding the risks associated with the deficits the child now has. Our brain injury assessment tool enables schools to better understand the needs of these children, that as our Case Studies show; are often overlooked and misunderstood by Education Psychologists; CAMHS and other professionals. Often their assessment tools are not appropriate for brain injured children and young people.
- 11.12 For example, a brain injured child we are supporting has recently had their reading age assessed. The school were delighted to discover that they had an advanced reading age. However; what the test did not pick up was that whilst the child could read the words; they did not understand what they had just read. The passage was meaningless. As such this test is not appropriate to identify the needs of a child with an acquired brain injury.

12.0 RECOMMENDATIONS

- 12.1 That MP's note the findings of this report and take this forward to review and improve services for brain injured children and young people; ensuring they are not signposted to inappropriate mental health provision.
- 12.2 That public services pool resources to continue to fund this much-needed and ground-breaking service, with the addition of Case Management Workers and some p/t admin support. This proposal will be more cost effective for funding.
- 12.3 That the findings are used to improve services to children and young people who are living with an acquired brain injury and that the needs of these vulnerable children are highlighted and prioritised.
- 12.4 That the parent carers of brain injured children are better informed by paediatricians and provided with the information they need in discharge letters to enable parents to properly care for their child; be aware of the potential risks; and make informed decisions in the community based on their child's needs. This information will also assist community professionals to recommend and commission the most appropriate service for children and young people.

- 12.5** That paediatricians and GP's are better trained in understanding acquired brain injury and its ongoing complex effects on a child's developing brain and its impact on day to day life. Only then will children and young people receive a referral to the most appropriate service.
- 12.6** That systems are implemented in A&E departments to record the number of head injuries children have sustained and flag up to paediatricians where more than one head injury has been sustained in children.
- 12.7** That the incidence of paediatric acquired brain injury is significant enough to be prioritised in the Joint Strategic Needs Assessment of all local authorities, so they can plan for the current and future health and well-being needs of local neurologically impaired children, young people and their families, and to inform the commissioning of health, wellbeing and social care services.
- 12.8** That children and young people who are living with an acquired brain injury are included on the Register of Disabled Children to help to remove the discrimination they currently face.
- 12.9** That children and young people living with an acquired brain injury are recognised as a Child in Need because of their neurological deficits and be accepted for an EHC Plan accordingly.
- 12.10** That Police, and other public bodies who question children and young people are made aware of the complex effects of acquired brain injury and the deficits it creates to children's neurological functioning (physical, cognitive, communication, emotional and behavioural) and its potential to impact on mental capacity.
- 12.11** That the NHS and Public Health Departments implement an awareness raising campaign about the significance of head injuries on children; and particular, the impacts on a child's developing brain, to help prevent traumatic brain injury.
- 12.12** That **all** the ongoing neuro-rehabilitation and support needs of children and young people are considered during the discharge planning process across all domains; not just their immediate physiotherapy, SALT and OT needs. Many of the impairments will continue to emerge for many years to come; thus they need to be flagged to other multi agencies.

Report Author: Jan Rock
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For and on behalf of MATRIX Neurological