

Wasted lives – missed opportunities

Background to the project

Attention deficit hyperactivity disorder (ADHD) is a highly genetically predetermined disorder that affects sufferers in many ways throughout their lives. The core symptoms of impulsivity, inattention and hyperactivity give rise to a plethora of difficulties that affect behaviour, emotions and the ability to learn social skills. Undiagnosed and untreated ADHD leaves young people vulnerable, marginalized and at a great risk of not achieving their birthright potential.

Mary grew up in care, rejected at birth by the parents she doesn't know. Being 'different' at school she soon found that she had few if any close friends. Always on the go, never resting, never stopping to seemingly draw breath, Mary out paced her peers and led a solitary young life. At times outspoken in the foster home, Mary was often punished for being wilful and for expressing herself with 'tantrums' and anger. Carers couldn't cope with Mary and by the age of five she had been looked after by four different families as well as having spells in council run care homes. As Mary grew older other children shunned her, her self-esteem got lower as teachers called her stupid and punished her with endless detentions and withdrawn privileges. At the age of eleven, having being totally humiliated by her teachers for her poor academic performance Mary set fire to her school. It was raised to the ground. The police caught Mary; she had remained in the school grounds, fascinated by the fire. She was referred to a psychiatrist and over the next five years diagnosed with three different, and conflicting mental health disorders. For one period of six months she was forcibly kept in secure accommodation, as she was deemed too ill to be allowed into society. Mary was receiving no education worth noting, the inputs she did get were inadequate. She didn't concentrate, she didn't care and she didn't actively participate. She became more and more defiant and was rejected by all those around her. At nineteen, uneducated, Mary was a reject from society, a criminal, a habitual drug taker and an alcoholic. On many occasions she had attempted to take her own life, she felt it wasn't worth living. Thankfully, and unusually, Mary was then recognised by a specially trained social worker as possibly having ADHD. After many struggles the social worker had Mary seen by a specialist psychiatrist who confirmed her ADHD and prescribed medication for her. Mary became motivated to do better, went back to college and in a single year sat three 'A' levels, all of which she passed with flying colours. She is now under the regular care of a leading psychiatrist and she is a student at Cambridge. Mary, in reality, was lucky, not many young people with ADHD have such a happy ending.

A ground breaking project being orchestrated by officers in the Lancashire Constabulary is addressing the needs of the many Mary's in the County with a commitment to altering the trajectory from genetic disorder to a chaotic lifestyle and giving the ADHD sufferers of Lancashire a greater chance to achieve their birthright potential.

It is vital that we understand the biological, psychological and educational issues within ADHD and the inherent need for collaborative inter-agency approaches to achieve success. Within the Lancashire project, managers and key workers from a wide range of agencies are presenting an alternative future to young people.

This paper outlines why Lancashire Constabulary's DDAP (Development Disorders – Achieving Potential) project is gaining national and international recognition.

The DDAP project

Lancashire Constabulary's solution is based on three separate foundations:

- Previous academic research on ADHD and its affects on people's lives
- The existing knowledge and experience of experts from around the world, and
- The fertile ground that is allowing for a step change in public services with the advent of a changing political agenda for preventative services.

The project has developed a multi-agency framework for service provision that has a focus on the performance criteria of the individual agency, rather than expecting participants to alter their organisational focus to one of crime reduction. Should the agencies involved in DDAP assist the relevant young people to achieve their potential, an anticipated outcome, it is an expectation that entry into crime or recidivism will naturally reduce as a direct consequence.

DDAP has deliberately not restricted the activities of the project to a single age group, within the alliance framework participating agencies concentrate on the catchment age profile of their existing client group, e.g. for Connexions this would be up to age 19 years whilst for the police involvement this would stretch beyond this boundary.

23% of crime is committed by people with undiagnosed or inadequately treated mental illnesses such as ADHD¹. 5% of the general population are believed to suffer from ADHD yet in 2001 her Majesty's Inspector of Prisons reported that up to 50% of the prison population had some form of mental illness. Reducing the disproportionate nature of this population / prison balance is a driving force behind DDAP.

The project is located in the boroughs of Burnley and Pendle, both of which are in East Lancashire, an area of higher than average deprivation. The decision to locate the project in East Lancashire was made due to the high levels of commitment and support within the East Lancashire Child and Adolescent Mental Health (CAMHS) team and the governing Primary Care trust (PCT).

DDAP is managed through a project board. Each participating agency has a place on the board, but where agencies are clustered around a delivery theme, e.g. schools and education psychologists, one person represents the 'theme' at the monthly meetings. Thus the board is tight, focused and able to make decisions expediently and effectively.

DDAP has representation and participation from the majority of agencies that could be involved with mental health sufferers in the wider context. At the younger age bracket are health visitors and Sure Start staff whilst in the more senior category Social Services, the police and the voluntary sector are active contributors.

Additional vulnerabilities and co-current issues frequently manifest within ADHD sufferers. DDAP is engaged with a wide-range of partners to tackle headlining issues such as: -

- Teenage pregnancies, addition risk of unwanted pregnancy is 41:1
- Community drugs teams acknowledging that ADHD and associated co morbidities provide higher risk of a fast track into substance misuse
- Domestic violence groups working with offenders and victims acknowledging that ADHD leaves a person nine times more likely to be involved in domestic violence
- Youth offending teams tackling the increased risk of re-offending from 1.7% within the 'normal' population to 31% within the ADHD population

¹ British Medical Journal. Article 3197, 23 May 1998.

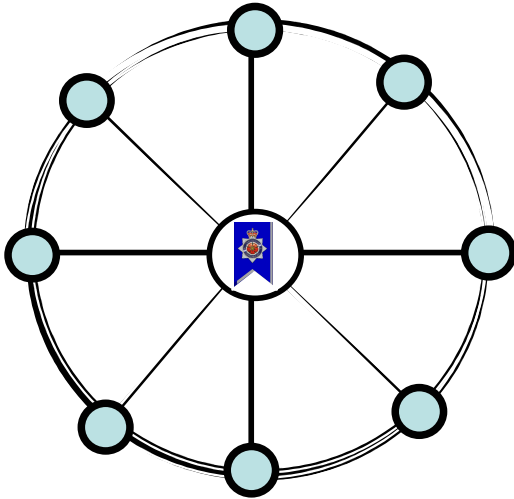


Fig 1.
Wheel and spoke

Communication and liaison is a vital component of DDAP. The board have developed a 'wheel and spoke' philosophy, whereby agencies work in alliance to identify mutually beneficial service improvements and to assist the 'greater good' of the project. Co-funded posts, support across agencies for the common goal, such as parenting training, are exemplars of true multi agency activity that has occurred within DDAP.

The combination of the statutory agencies plus the voluntary sector brings an unparalleled strength into DDAP. The voluntary sector offers a level of expertise and practical assistance that reaches far beyond the existing levels of competence found amongst core service providers. Agencies such as ADDISS, the national ADHD support group, are therefore a principal component of DDAP.

Parenting groups had previously struggled to get support and help when parents themselves recognised their child was getting difficult to control. The newly formed parent support group, built into the management of the project, offers support and a signpost into the participating agencies.

Partner agencies have each produced an individual, mental health specific action plan as part of the DDAP process. Uniquely these plans include three elements, i) what the agency recognises as service improvements, ii) what the agency recognises it needs to higher standard from partners and iii) what the agency can deliver, with the project in mind, to higher standard to partners. As a suite of DDAP development plans these are quality assured by ADDISS, a process that places the voluntary sector at the forefront of the project. The model, referred to as the 'handshake model' is instrumental to the development of true allied services across the participating agencies.

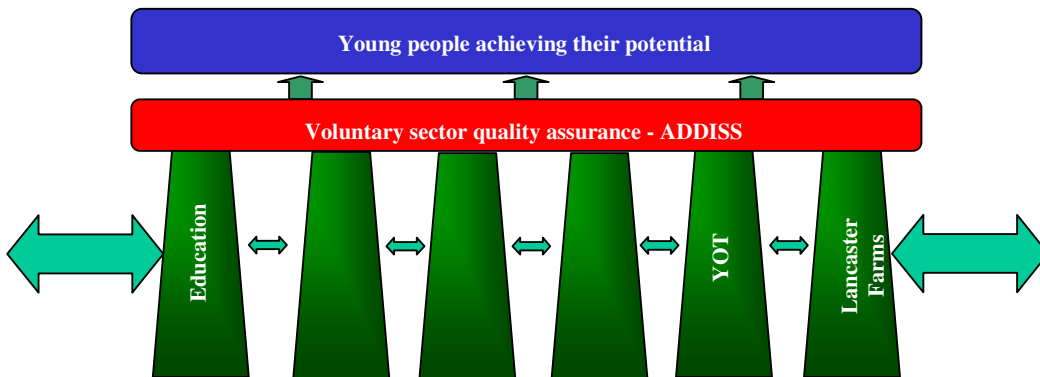


Fig 2.
Allied services handshake model

Feedback from parents, carers and sufferers of ADHD indicate that having to access services individually is itself a barrier to progress, let alone the additional obstacle that ADHD in the family can bring about. A key aim of DDAP is to provide care pathways for parents, carers and sufferers to reduce the maze of services into a more organised and identifiable allied service. The provision

of a Multi Agency Care Pathway (MACPATH) and the associated wrap around services will remain the centre of attention whilst DDAP matures.

Activity focus

Untreated or undiagnosed ADHD leaves young sufferers vulnerable to failing to achieve their potential, a trajectory that leads directly to wasted lives. DDAP is designed to alter the course of that trajectory and to help sufferers and their carers to break the cycle.

Educational achievement, or lack of, social marginalisation, depression, absenteeism from the home and school, residing in care, entering the criminal justice system, depression, drug abuse and being extraordinarily accident prone are some of the more common associations with untreated or poorly treated conditions such as ADHD.

Sufferers frequently have behavioural difficulties that co-exist with the core issue. ADHD sufferers often cannot effectively 'read other peoples faces', a core component of any meaningful interpersonal activity, they often show a lack of restraint, especially when under stress and, worryingly for parents, young people with ADHD are often gullible and easily led by others. Emotional development within the ADHD person is often slower than the 'norm' and scientists have recently claimed that the emotional 'fallback' is up to one third. Imagine an eighteen year old with an undiagnosed emotional ability of that more akin to a twelve year old.

Not all young people with ADHD go wrong, however, most are at a heightened risk of educational underachievement. With the existence of additional risk factors such as hostile parenting, the probability of reduced opportunities is inflated considerably.

This project reduces the vulnerability of ADHD sufferers by providing a two storey service. On the ground floor, services such as SureStart, schools and Connexions aim to identify and assist in the early diagnosis of ADHD. Thus, through DDAP, they place individual sufferers and their families into a co-ordinated multi agency pathway of care. Should this initial level of service fail to prevent young people having reduced risk, thereby entering into the justice system, the participating agencies such as the Youth Offending Team, special education needs and the police offer another opportunity for the individuals negative trajectory to be re-aligned.

Under the leadership of Lancashire Constabulary, DDAP has three main focal goals all of which are seen as consequences of more young people achieving their potential

- 1. reducing crime and substance misuse**
- 2. reducing anti social behaviour (ASB)**
- 3. reducing road traffic casualties**

1. reducing crime and substance misuse

Returning to the crime based agenda, the failings of the neuro-pathways within the ADHD brain are cited as the causes of the behavioural traits mentioned above. Treatment with prescribed medication, such as methylphenidate, for instance Ritalin, increases the effectiveness of those pathways and so reduces the negative behavioural manifestations that give rise to so much concern. Recent research has identified that sufferers can 'self-

medicate' through the use of illegal drugs, such as cocaine and heroin, both of which have a similar effect on the brain to methylphenidate.

Therefore, within the rationale for DDAP, the reduction of substance misuse, through diagnosis and appropriate medication is a goal that could directly lead to greater achievement and less crime.

2. reducing anti social behaviour

Anti-social behaviour is a frequent matter for discussion within observers of ADHD and its associated co-morbidities. Typical responses to young people who cause civil disruption is through anti-social behaviour contract (ABCs), interventions such as positive activities, anti-social behaviour orders (ASBOs) and where already within the YOT clientele, reparation orders and detention training orders (DTOs). DDAP aims to ensure that such contracts and legal undertakings are made ADHD tolerant, thus increasing the probability of successful completion.

3. reducing road casualties

When the behavioural characteristics of ADHD are discussed in detail, i.e. inattentiveness, an inability to concentrate for long periods and a prevalence to act on impulse, the links to road casualties become clearer. Published research outlines how young men with untreated ADHD are four times more likely to have a road collision², and youngsters with ADHD in Germany were found to be 9 times more likely to suffer an accident on the roads as a pedestrian³. DDAP is embarking on education programmes for the ADHD road user and is seeking a greater level of awareness amongst parents, carers and professionals within the field of driving.

ADHD and courts youth offending teams and prisons

Studies claim that a minimum of 5% of the population have ADHD yet the Institute of Psychiatry indicate that 25% of a sample group of ADHD sufferers had been to prison⁴. Her Majesty's Inspectors of Prisons stated in 1997 that 50% of young people on remand in the UK suffer a mental health disorder and 30% of those sentenced also have a mental health disorder⁵.

A focal area of the project is an improvement in the services provided to offenders, pre-offenders (through the local YISP) and for those incarcerated at Lancaster Farms (YOI). Where appropriate, training will be given to CPS and the court services regarding mental health and ADHD to ensure that interventions and sentencing decisions are made in a manner that supports the offender's mental health and gives every chance of effective rehabilitation.

Within the YOI the level of psychiatric service is regarded by the prison service to be inadequate. DDAP will draw on contacts and the emerging influence to ensure that a more effective provision is an outcome of this project.

Overall

Nothing matters more to families than the health, welfare and future success of their children. Our future depends on the fulfilment of dreams, hopes and potential of our children being realised.

² Barkley RA. et al. Paediatrics 1993; 92: 212-218

³ Federal Agency for Occupational Health, Safety and Medicine, Germany. (2001)

⁴ Dr Susan Young, Speech to British Psychiatry Society, Annual Conference, March 2001

⁵ Young Prisoners ISBN 1-85893-998-4

DDAP members have a system that is reasonable and likely to work, because it is a model based upon good practices and solid foundations, such as robust academic research, considerable knowledge amongst participating agencies and the emerging, and changing, political agenda. Further requirements of DDAP exist, when provided these will ensure that the project maintains effective and complete solutions. Those requirements are: -

- The provision of a jointly funded ‘conductor’ to orchestrate activity to maximise effect across participating agencies, such a professional would be an educationalist or specialist nurse
- Re-alignment of corporate decision making, especially co-coordinated long term funding, to ensure the efficacy matters of dealing with ‘special measures’ are understood and moved away from the current ‘too much – too late’ scenario
- Higher levels of investment in recruitment and training of professionals such as teachers, health workers, police officers, and youth workers to overcome the skills deficits that this work has highlighted and addressed within its locality

In conclusion, agencies and their staff need to work in close alliance to orchestrate the most effective solutions, in particular, as seen in DDAP, professionals and carers should be in a position to answer three fundamental questions: -

<p style="text-align: center;">What does ADHD look like?</p> <p style="text-align: center;">What do I need to do?</p> <p style="text-align: center;">Who else do I need to assist me?</p>
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DDAP is establishing itself as a tested model to achieve the framework goals. As a pilot project DDAP needs to prove the value of the systems and processes within its framework. In doing so this project will present prima facie evidence that justifies re-alignment of budgets and services within existing provisions of social, and welfare care.

