

- November 2020
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Public Health Leicester City
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Aims

- Discuss the context of ADHD in Leicester City
- What is ADHD?
- Impact of ADHD on children, young people, adults and their families
- Service provision –
 - What we have
 - What would a gold standard NICE compliant service look like
- Call for Action



How many people in Leicester have ADHD?

- Estimates show 2% to 5% of school children have ADHD - equates to between 1,100 and 2,800 children in Leicester;
- Prevalence of ADHD in the adult population is between 3% and 4%, the majority are undiagnosed - equates to 8,000 to 11,000 people aged >18 years.





Emma
Watson



Will
Smith



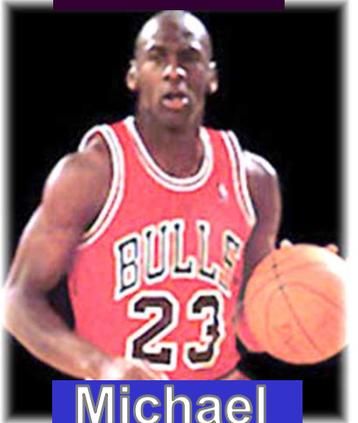
Justin
Timberlake



will.i.am



Rita
Simons



Michael
Jordan



Channing
Tatum



Michelle
Rodriguez



Zayn
Malik



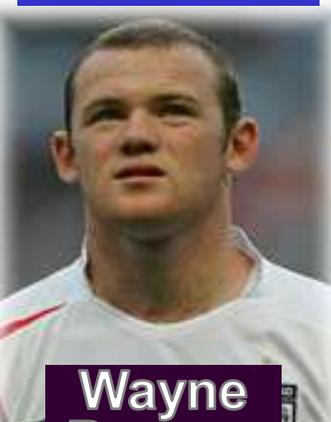
Lee
Evans



Michael
Phelps



Richard
Branson



Wayne
Rooney



Britney
Spears



Simone
Biles

What is ADHD?

ADHD fact

It is a common, complex neurodevelopmental disorder that affects many people for their whole life

ADHD fiction

“It’s just naughty kids”

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ADHD is not a ‘label’

It’s a recognised diagnosis of a complex disability



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Causes

The exact cause of attention deficit hyperactivity disorder (ADHD) is not fully understood, although a combination of factors is thought to be responsible.

Genetics

However, the way ADHD is inherited is likely to be complex and is not thought to be related to a single genetic fault.

Brain function and structure

Research has identified a number of possible differences in the brains of people with ADHD from those without the condition, although the exact significance of these is not clear.

Groups at risk

Certain groups are also believed to be more at risk
Eg Premature birth, with epilepsy, with brain damage,
Prenatal exposures, such as alcohol, nicotine from smoking,
substance misuse



What does it look like?

it's **NOT**
just about
this → **H**

You **DO NOT** need to be
Hyperactive to be
diagnosed
with ADHD



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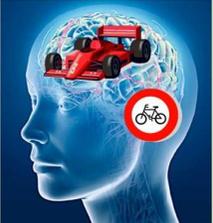
The most **common**
feature of ADHD is

Inattention
not **Hyperactivity**



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Emotional Regulation can be a challenge for people with ADHD. It's been described as having a...



Racing Car Brain (going '0-100' too fast) with **Bicycle Brakes**

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Poor short-term memory ...is a common feature of **ADHD**

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People with **ADHD** are known for thinking **OUTSIDE the BOX**



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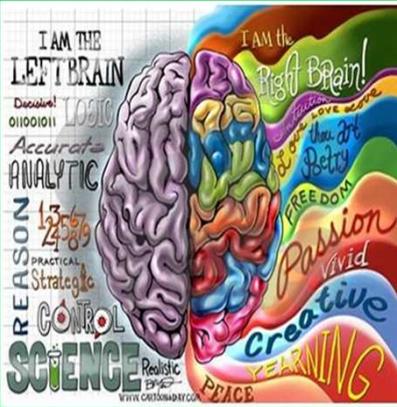
People with **ADHD** are good at **spotting** things that others **miss**



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I AM THE **LEFT BRAIN** I AM THE **Right Brain!**

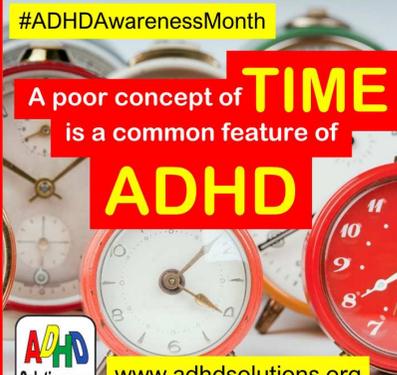


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A poor concept of **TIME** is a common feature of **ADHD**



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Girls with **ADHD** are too often **missed** as they **don't display** 'obvious' signs and **mask it** too well

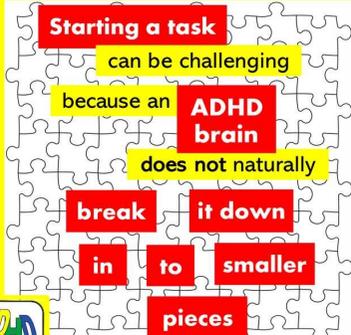


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Starting a task can be challenging because an **ADHD brain** does not naturally **break it down** in to **smaller pieces**



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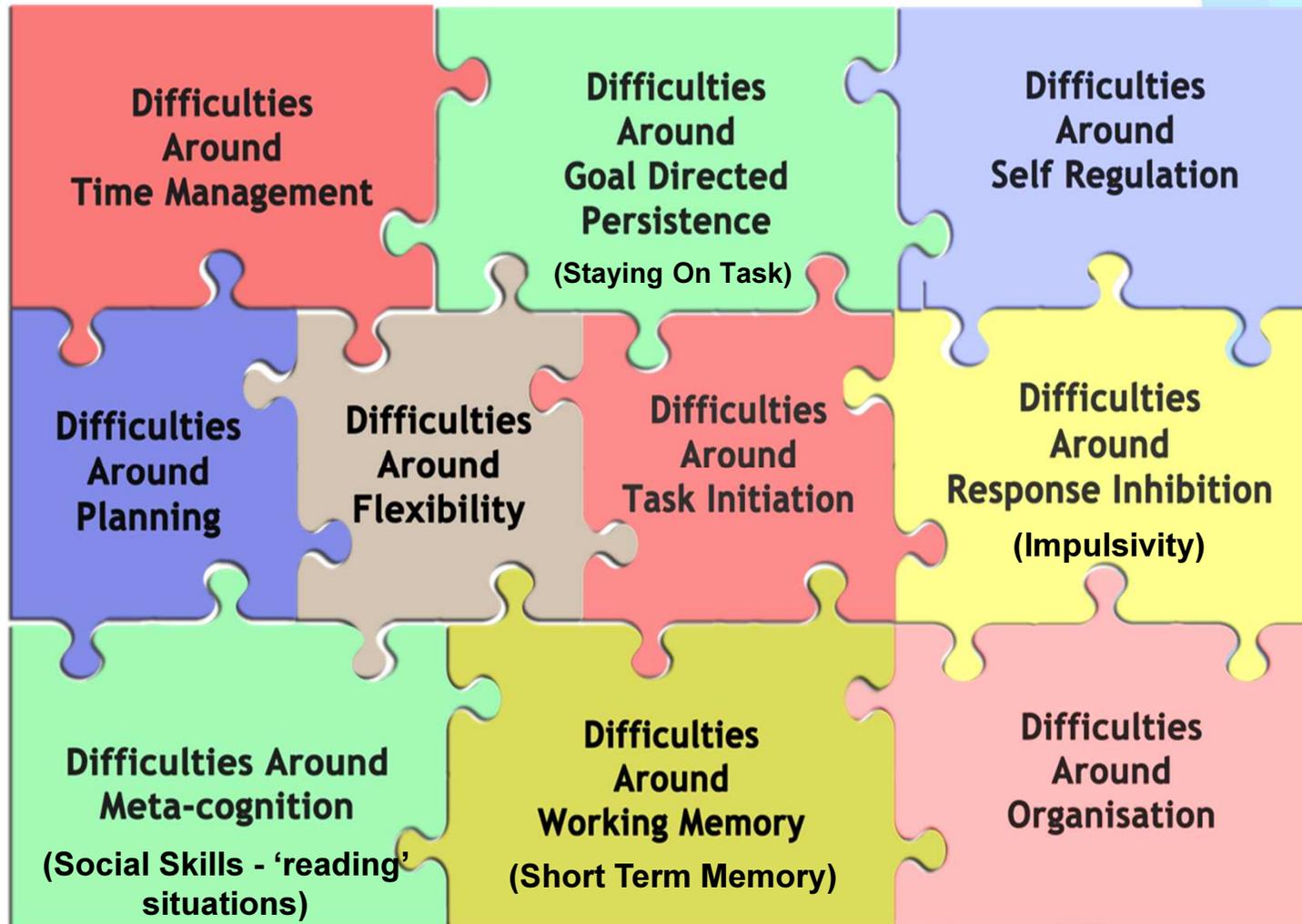
ADHD Difference or Disorder?

+ **imaginative** energetic **creative** innovative inquisitive **enthusiastic** think **willing to take risks** out **good at visual thinking** side **the box**

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ADHD and Executive Functions



Positive Attributes of ADHD...

- Creative
- Highly questioning
- Imaginative
- Sensitive
- Inquisitive
- Innovative
- Willing to take risks
- Tremendous energy
- Divergent thinker i.e. thinking 'outside the box'
- Keen to take part and contribute
- Persistent
- Perfectionist
- Good at visual thinking
- Highly aware of the environment around them
- Sharp observational skills
- Single minded when pursuing an opportunity or interest

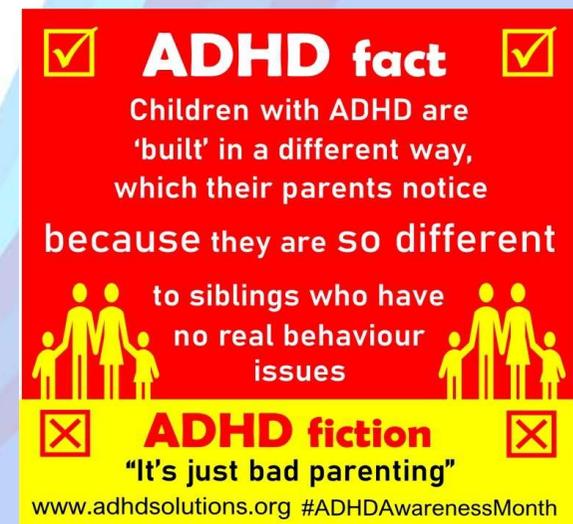
...Difference or Disorder?



How does a diagnosis impact on families?

Initially

- **Relief** – I've been listened to there is a reason for my child/partner/own behaviours
- **Emotional impact** - Exhaustion when the fight to be **heard** is over, but the hard work begins
- **Bereavement** – I have a child with a disability / what could my life have been?
- **Lots of barriers** – difficulty getting recognition and support
- **Guilt** - I feel like it is all my fault.
- **Exhaustion** – ADHD is constant



ADHD fact

Children with ADHD are 'built' in a different way, which their parents notice because they are SO different

to siblings who have no real behaviour issues

ADHD fiction

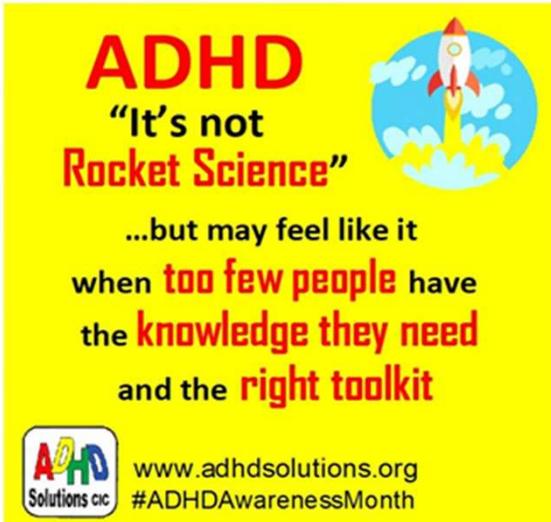
"It's just bad parenting"

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The graphic features two family icons: one on the left representing a family with a child with ADHD, and one on the right representing a family with a child without ADHD. The background is red for the 'fact' section and yellow for the 'fiction' section.

What impacts on the outcomes of someone with ADHD ?

- Age of diagnosis
- Parental ADHD – intergenerational predisposition to ADHD
- Knowledge, awareness and understanding of ADHD by teachers, school staff, other professionals, workplace managers/colleagues
- Knowledge, awareness and understanding of ADHD by extended family and the community services
- Education and support for children / young people and adults to understand and manage their executive functions



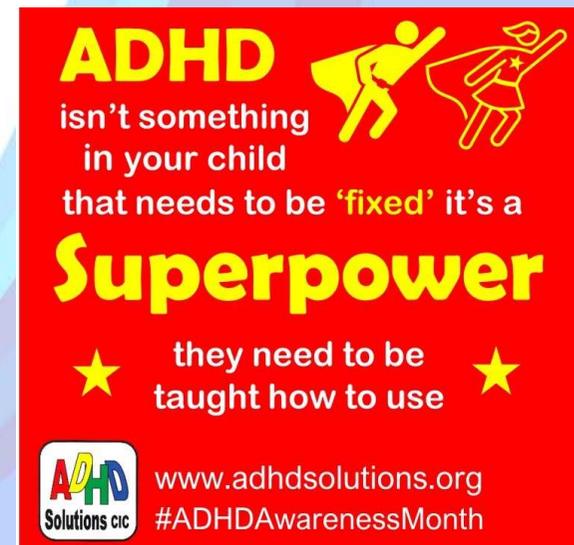
ADHD
“It’s not
Rocket Science” 

...but may feel like it
when **too few people** have
the **knowledge they need**
and the **right toolkit**

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What do people with ADHD and their families need?

- ❑ Someone to talk to – who is non judgemental
- ❑ To learn more about the condition
- ❑ support with crisis situations at home, school and in the community
- ❑ Find some practical solutions and advice to manage the challenges they face
- ❑ Support with challenges at school, college & work
- ❑ Activities/social interaction
- ❑ Benefit/housing support
- ❑ Advocacy



ADHD isn't something in your child that needs to be 'fixed' it's a **Superpower**

★ they need to be taught how to use ★

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The graphic is a red rectangle with yellow and white text. It features two yellow stick figures with red capes, one in a dynamic pose and one in a more static pose. The text is arranged in a clear, bold font, emphasizing the message that ADHD is a superpower that should be taught how to use rather than fixed. The logo for ADHD Solutions cc is in the bottom left corner, and the website and hashtag are in the bottom right.

To know that they/their child
can be happy and fulfilled
and reach their true
potential regardless of their
diagnosis.



What are the hardest things to cope with?

Isolation

Being excluded from family and peer group activities.

'Unless you live with it, you can't comprehend the difficulties parents and siblings have to go through'

School

Navigating the education system

'When a child has behavior problems it can be extremely difficult dealing with schools – even when a diagnosis has been made. Meetings and discussions with teachers can be very daunting, and very often teachers and assistants are at a loss as to how to deal with classroom situations ADHD people are very unpredictable. I love my son but not his condition.'



Family relationships

Families are at much higher risk of family breakdown, domestic violence, social and emotional difficulties including self-harm/suicidal ideation, they often experience poorer mental health, greater parenting related stress, lower parenting self-esteem, be at greater risk of depression, and have greater alcohol consumption

'I used to feel like the worlds worst parent, managing my kids and partners ADHD is so hard its like having 3 kids! Many a time the ADHD has threatened to split up the family'

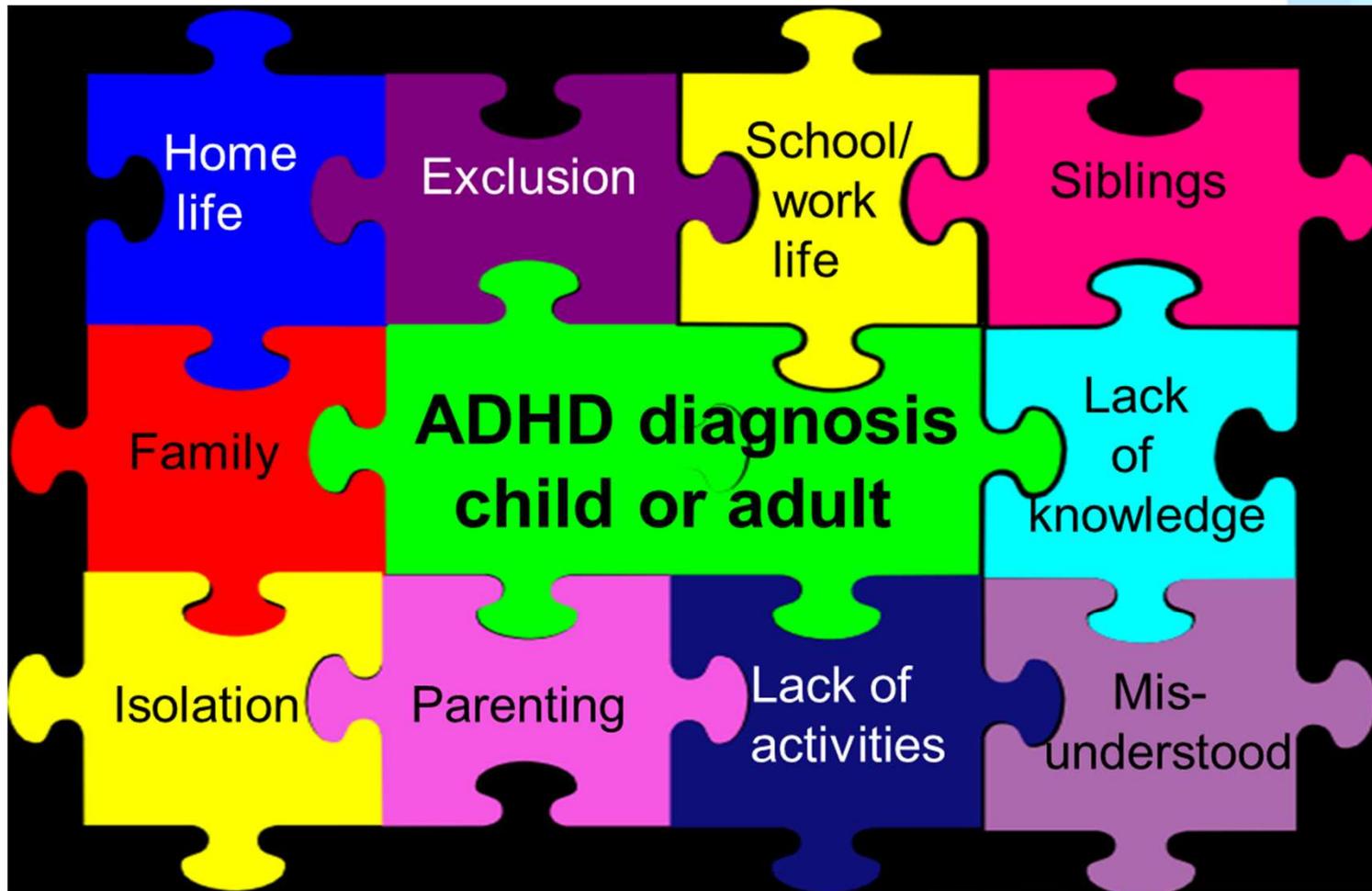
Work

Adults find it much harder to stick to a job and are at a much higher risk of economic underachievement

<https://nottingham-repository.worktribe.com/output/4300282/what-is-the-health-and-well-being-burden-for-parents-of-living-with-a-child-with-adhd-in-the-united-kingdom>



An ADHD diagnosis is just a part of the jigsaw



What does NICE (2018) say an ADHD Service should provide

- Education about the condition for all patients, parents and carers
- Provide Information about treatment options
- **ADHD-focused group parent-training programme** to parents or carers of children under 5 years with ADHD as first-line treatment
- Offer group based and ADHD focused parenting support as the first approach to parents and carers of all children aged 5 years and over and
- Offer group based and ADHD focused support as the first approach for young people with ADHD.



ADHD Solutions offers



Case study -

Jack was diagnosed and medicated by his Paediatrician in 2007 age 10 yrs following a referral from school for hyperactivity, inattention and disruptive dangerous behaviour. Jack has intermittently taken medication to the current day, taking breaks when under pressure from his peers to fit in.

He was referred to our service initially for Education/information, parenting, and behaviour support in the form of 1-2-3 Magic and ADHD Coaching, and activities and social interaction to develop his social skills and self-esteem.

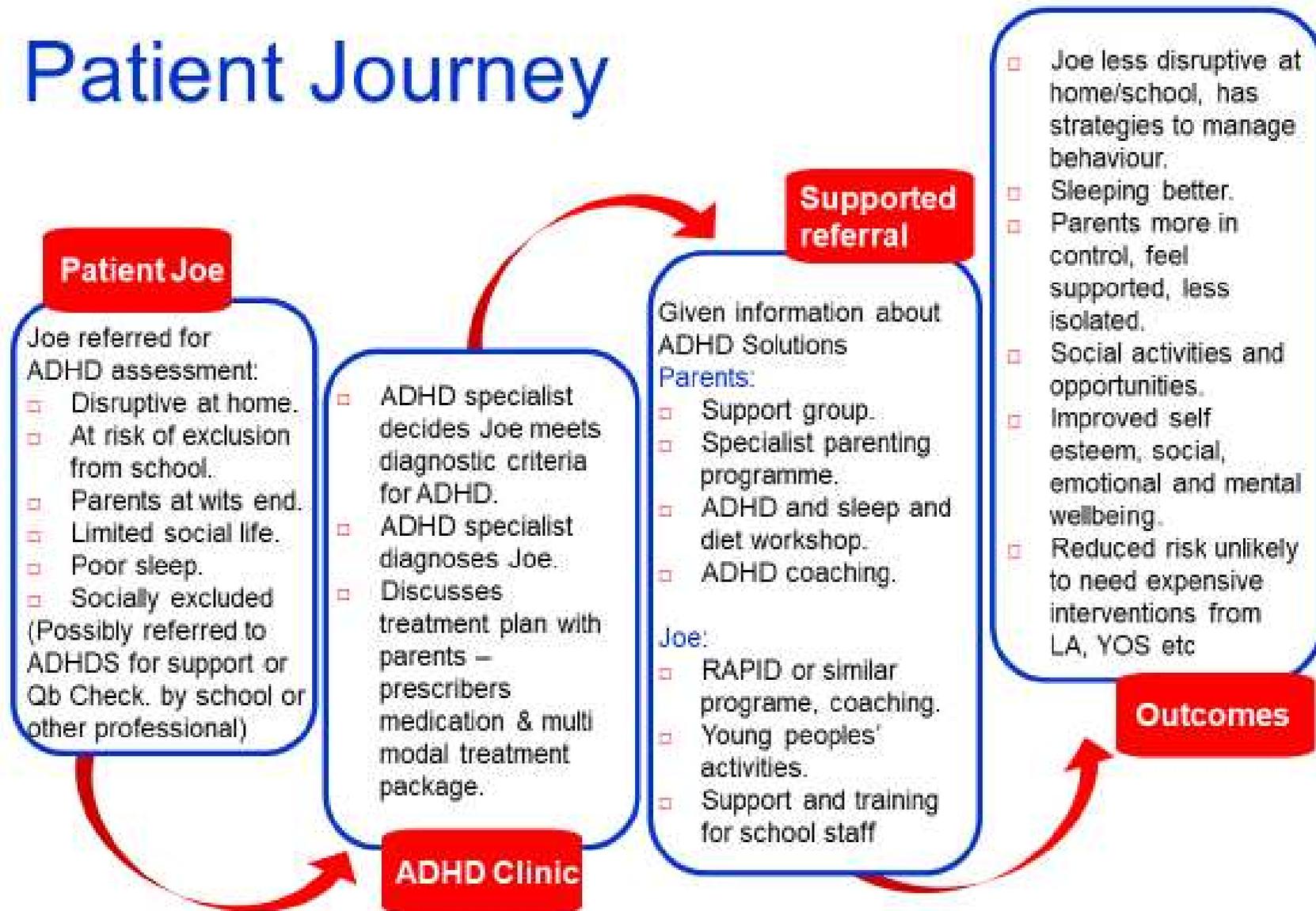
Subsequently to support Jack in the classroom, school support for his class teacher and whole school training – Primary school, secondary school and college were under taken at the schools expense.

Over the last 11 years Jack and his family have dipped in and out of our service as he/they have needed some additional support – usually around the time of transition, attending various workshops and youth activities, culminating in an adult ADHD Life skills program.

Over this time he has learnt to manage his ADHD in all areas of his life and achieved 14 A-C GCSE's, B-lect Diploma in Sports with a distinction star, he has worked with young people with ADHD during summer activity programs and is now working fulltime with the elderly. He is independent, married and expecting his first child later in the year.

Quote ' I took medication which helped me focus and learn but I wouldn't be able to manage or where I am today with out the training and coaching me and my mum had, it gave me the foundations for everything I do.'

Patient Journey



What would a gold service look like?

- Swift assessment process
- Early diagnosis
- Information about treatment choices
- Education about ADHD for parents, carers and professionals
- Age appropriate education about ADHD for people diagnosed with the condition
-



What would a gold service look like?

GOLD service

- Swift assessment process
- Early diagnosis
- Information about treatment choices
- Education about ADHD for parents, carers and professionals
- Age appropriate education about ADHD for people diagnosed with the condition
- Support to manage co-occurring difficulties eg sleep
- Support for professionals
- Perinatal and post natal support for ADHD parents

Current service

- Slow assessment process
- Long waiting lists
- Information about treatment choices patchy

ADHD Solutions Service

- Education about ADHD for parents, carers and professionals
- Age appropriate education about ADHD for people diagnosed with the condition
- ADHD Coaching & family Support
- Support for professionals



Cost of ADHD to the public purse

There are many papers studying the costs of ADHD.

*C Telford et al, 'Estimating the costs of ongoing care for adolescents with attention-deficit hyperactivity disorder' (2013) focused on the burden of ADHD to the public purse. And estimated the additional education, health and social care costs among adolescents in the UK diagnosed with ADHD is **£5,493 per young person per annum***



What do the letters mean to you?

A **WESOME**

D **etermined**

H **EROIC**

D **ifferent**



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Call to Action

Parity of esteem with neurodevelopmental disorders needs:

More accurate information about the number of people with ADHD in Leicester;

Improved knowledge about ADHD across health and social care;

Better access to secondary care for expert diagnosis;

Post-diagnosis support for people with ADHD and their carers.



Questions for your organisations

- Is there parity of esteem for people with ADHD?
- Do people know about and understand ADHD?
- Are there holistic assessments for people with ADHD?
- Is there discrimination against ADHD? Is it challenged?



For more information...

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ADHD Solutions UK



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