



# ***Partnership Working: Creating the Possible***

(Circles Network,  
2001)

# A Parent / Carer's Perspective

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# Who am I?

# Why am I here today?





How could we start to create **effective partnerships** and **customise the boys' education** in a culture that felt as though **professionals** ration and **we** had to beg; where we could see no easy fit for our two children and it felt like professionals had all the **power** and the system had taught us to be **dependent** ?



### The person:

Bright and funny  
Walked at 10 months, could read by age 3  
Head Boy at Primary School and swam for the local swimming club  
Brilliant at technology and building / fixing just about anything!



## J's story Born 1996

### The label:

High functioning autism  
ADHD / Impulse Control Disorder  
Significant sensory impairment  
Severe challenging behaviour



## **J's educational journey to age 17.....**

- First nursery 'could not cope' and asked him to leave after one month
- Very happy and thrived in second nursery and infant school
- Local primary 'could not cope' by Christmas in Year 3 ....Statemented
- Out of school for two months aged 7
- Went to independent prep school Year 3 to Year 6 funded by his Statement, and thrived again
- Went to local secondary school in Year 7, lasted till Christmas – 'too dangerous'
- Out of school for 5 months
- Sent to residential special school for boys with high functioning autism / Asperger's in Oxfordshire in June of Year 7
- Excluded in September of Year 9 and labelled as 'psychotic' due to 'challenging behaviour'
- Out of school for 8 months
- Went to 'highly therapeutic' 'high cost' residential setting in Cumbria for boys with autism and complex and challenging behaviours at Easter of Year 9
- Place terminated by the school in Year 12 after he made a formal complaint

**J returned home in June 2014 with high ambitions but no support and no educational provision**



### The person:

Bright and funny  
Great hand / eye coordination, good at sports  
Could ride a bike at 2 ½  
Has corporate sponsorship as a skater  
Excellent drummer and guitarist  
Was a School Prefect  
Loves to be outside!



## T's story Born 1998

### The label:

Tourette Syndrome  
ADHD  
Dyscalculia  
Mild Learning Difficulties  
Behavioural, Emotional and Social Difficulties



## **T's educational journey to age 17.....**

- Very happy and thrived in nursery and infant school. Loads of friends but did not learn to read or write. Put onto School Action
- Moved T to the same independent prep school as J in Year 2 at age 6, paid for by us
- Diagnosed with Tourette's in Year 6 and missed two months of school
- Went to local secondary school in Year 7
- Severely bullied and struggling academically through Year 7. Received rest of diagnoses and moved onto School Action Plus
- Tourette's and bullying worsened in Year 8, began to access Forest School and CAMNET
- Statemented in Year 9. Moved to a Pupil Referral Unit as a vulnerable child. Began self-harming and became suicidal
- Removed from school by us at the beginning of Year 10 and home schooled for 8 months with support of Local Authority, Forest School and CAMNET
- Went to an independent mainstream school in April of Year 10 paid for via his Statement, dropped down a year to Year 9 and remained there very happily for rest of his education

**T reached the end of Year 11 in 2015 with clear career ambitions but no obvious stepping stone from school to get there.....**

## My Mainstream Life....

The boys were now young men, well into transition. Our focus was on how we could **flex the education and social care system** so they could explore what real inclusion could look like beyond school...



How could we give their unique gifts a chance to grow, and help them create possibilities and learn through trial and error in order to move into an adult world where they could be genuinely included and valued?

*“Young people in transition who become valued community members in pursuit of a dream, build more than a world for themselves, they also build a new world of possibilities for others.”*

(Mount & O'Brien, 2002)

## Personal Budgets and Section 3.38 of the 2014 Code of Practice:

Young people and parents of children who have EHC plans **have the right to request a Personal Budget, which may contain elements of education, social care and health funding.....including:**

- **direct payments** – where individuals receive the cash to contract, purchase and manage services themselves
- an arrangement – whereby the local authority, school or college holds the funds and commissions the support specified in the EHC plan (these are sometimes called **notional budgets**)
- third party arrangements – where funds (direct payments) are paid to and managed by an individual or organisation **on behalf of the child's parent or the young person**
- a **combination** of the above

(SEND Code of Practice 2014: 48)

## How we used the new legislation and Code of Practice for J:

- J wrote his own Person-Centred Transition Plan
- We decided Personal Budgets were the way forward, and found a small community organisation which was willing to work with us as a partner
- We worked very closely with the Local Authority SEN Head of Service and Social Services to agree a protocol and process in an area unfamiliar to us all, and J was moved onto an EHCP
- We created an individualised programme that was a mixture of classroom based learning, work experience, independent learning and setting up and running his own micro-enterprise, and used short breaks money towards driving lessons
- We worked with Health through Continuing Health Care to fund an independent psychologist who shares our values to work 1:1 with J for an hour a week



In the space of 18 months, J obtained Level 3 Diplomas in ICT and Business Entrepreneurship and Enterprise, and set up his own small gardening and IT micro business with TalentMatch Humber support and funding.

He made new friends, went to a Fake Festival with them and began volunteering at the local autism youth club as a mentor.

## How we used the new legislation and Code of Practice for T:

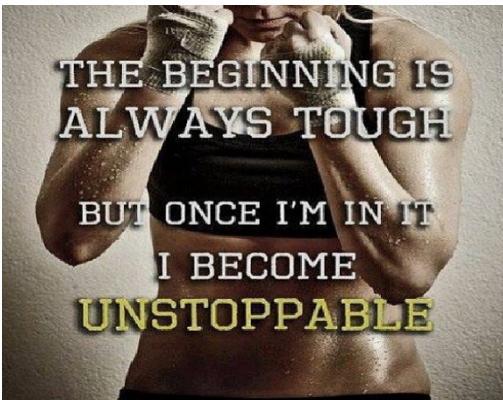
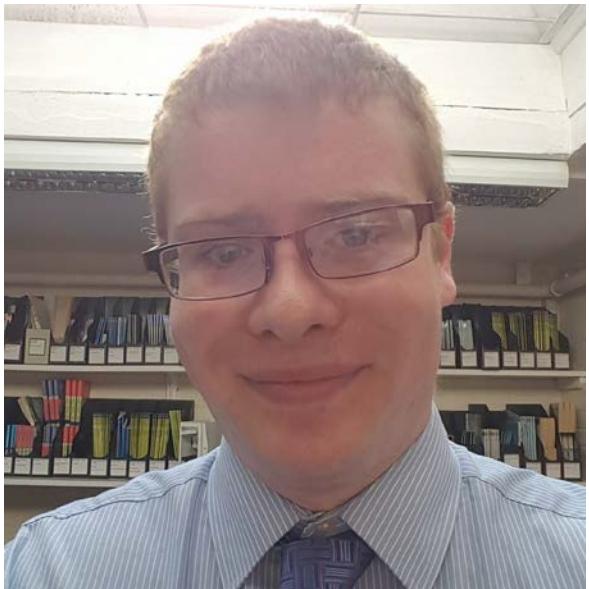
- T wrote his own Person Centred Transition Plan
- T was clear he did not feel College was the right environment for him. He did not feel ready to move on from his school and wanted to move into the 6<sup>th</sup> Form with his friends, but did not want to follow an exclusively academic programme
- We worked with T's existing school and the Local Authority to design a bespoke 6<sup>th</sup> Form programme that would help him to achieve his aspirations. This included AS Level Art, re-doing maths and English GCSEs but doing away with his learning support assistant and instead having 1:1 lessons with the subject teachers, building in additional pastoral support to work on emotional resilience and working with the local golf club to create a work experience placement for two days per week in green-keeping and estate management



T left school on the Friday at the end of the Summer term, and was successful in interview for his dream job as an apprentice in grounds maintenance, parks and open spaces the following Monday...

## J now at 19:

Has an Advanced Level Apprenticeship in IT, working across two really inclusive primary schools. He loves his job and advises staff and mentors youngsters on the Spectrum  
Has a small group of good friends, and a good social life  
Has passed his driving test and has his own car  
Receives no paid support at all except for his ongoing sessions with his psychologist

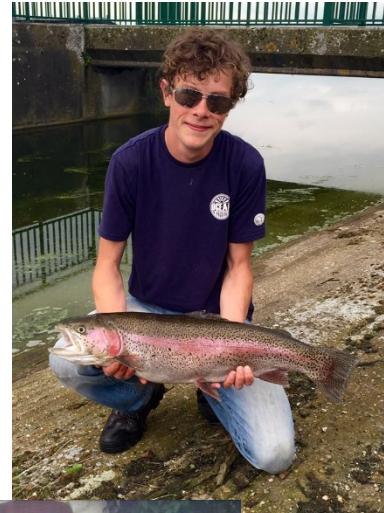




## T now at 18....

Has been working for four months and loves his job  
He has recently finished with his girlfriend of two years, and is enjoying the single life!  
Is learning to drive

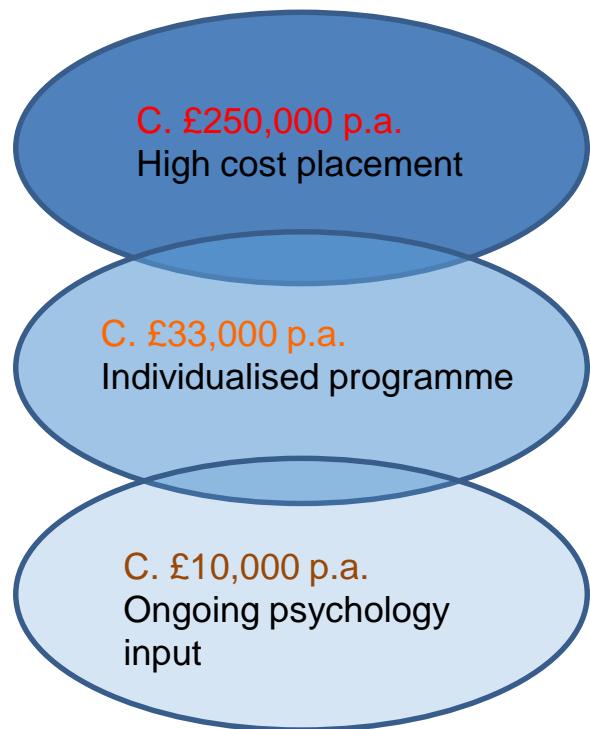
Has become a keen off road biker and has saved up and bought his own motorbike  
Still skates and is now sponsored by two companies  
Has a great group of friends who share his love of the outdoors and high adrenaline sports



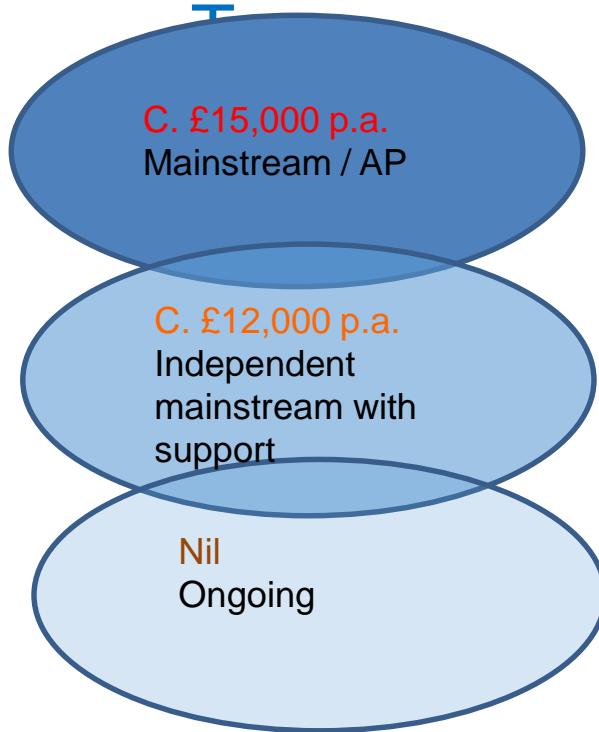
## “it’s the money, stupid”

With thanks to James Carville & Bill Clinton 1982

J:



T:





How on earth do we explain to employers, using a 'capacity' perspective?



## J's One Page Profile



### What is Important to J

- To be clear about what is expected of me and what your rules and boundaries are – I won't always 'get' this unless you tell me
- For people to be direct and honest with me. I don't like people who play mind games or expect me to guess the subtext
- To be organised – mess and confusion does not make me calm, even though I can be messy
- To be given clear and concise instructions and direction – I learn best by 'doing'
- To get on with people and be able to have a laugh and joke
- For people to accept me and treat me as the adult I am
- I love making, building and fixing pretty much anything
- To be left alone at times – I like my space personally and professionally
- To be recognised for trying hard even if I don't always succeed
- I am a bit of a 'techie' and enjoy fixing computers and building networks etc
- I am a major Star Wars fan...even my hamster is called Chewbacca!

### J's Strengths and Talents

**Very determined and hardworking**  
**Honest**  
**Practically minded**  
**Creative**  
**Good sense of humour**  
**Polite and professional**  
**Kind & thoughtful**  
**Willing to push himself and give things a go**  
**Loyal**



### How Best to Support J

- I am very literal in my understanding and use of language. I won't read your body language or facial expressions very well and can sometimes appear rude. Please just tell me directly if I have misjudged something
- Check that I have properly understood what you want me to do – I tend to work best if you show me rather than just tell me
- I find it hard to remember long lists given verbally, so sometimes need to write things down
- I always want to do a good job. I am flexible and work hard but I can be easily distracted and start obsessing about something. If you see this happening, please tell me to stop – you need to be direct with me
- To be busy is good, to be manic is not. I need to be clear what your priority is and what order you want things doing in
- Don't make me feel silly for asking for clarification – some things are not always clear to me
- If I feel too pressurized I can get anxious and my sensory differences get worse. Please let me take a short break if I need it – I won't take advantage!
- Get to know me...the rest will then speak for itself
- Let me know my work is valued/appreciated with regular feedback – you need to tell me, I won't just know...
- If you notice my tics, please ignore them. They are a sign I am a bit nervous / anxious
- Be aware too much sugar can make me very 'hyper' and I lose focus. Nudge me to not eat that extra chocolate bar!

(Sanderson, 2007)

# T's One Page Profile



## What we like and admire about T

*Strong-willed  
Honest  
Tries hard  
Good sense of humour  
Friendly/easy going with people  
Approachable  
Good at sport  
Kind & caring  
Genuine concern about others  
Loyal*

## What is Important to T

- To be clear about what is expected of me and what your rules and boundaries are
- To spend time outdoors and active – I love the countryside, fishing, shooting, golf, skateboarding, drumming, playing guitar and most sports
- To be surrounded with positive, welcoming people, not unpleasant or negative people
- To be organised – mess and confusion does not make me calm
- To be given clear and concise instructions and direction – I learn best by 'doing'
- To get on with people and be able to have a laugh and joke
- For people to accept me for who I am
- To have an up to date to-do list for everything and reminders / help to write this down
- To be left alone at times – I like my space personally and professionally
- To know I am doing a good job and making a difference
- To be recognised for trying hard even if I don't always succeed



## How Best to Support T

- Help me plan my time at the start of the day and ensure I have understood any instructions
- I work best as a team player - include me as part of the team...
- Be aware caffeine makes me very 'hyper' – don't give me too much coffee or coca cola or I lose focus completely. Energy drinks are my deadly enemy!
- I always want to do a good job. I am flexible and work hard but I can be easily distracted. If you see this happening, please give me a gentle nudge
- To be busy is good, to be manic is not
- Don't make me feel silly for asking for clarification – some things are not always clear
- Set deadlines/priorities for tasks, don't expect me to guess – this also helps me plan my work
- If I feel too pressurized I can get quite grumpy – please help me to think through the things that are worrying me but don't pander to my bad mood!
- Check that I have properly understood what you want me to do – I tend to work best if you show me rather than just tell me
- If you notice my tics, please ignore them. They don't affect my ability to do things safely but do get worse if I am stressed or anxious
- Get to know me.....the rest will then speak for itself
- Let me know my work is valued/appreciated with regular feedback

(Sanderson, 2007)

Albert Einstein once said:



*“Everybody is a genius....*

*But if you judge a fish by its ability  
to climb a tree, it will spend its  
whole life thinking it is stupid”*

# **The mother you see now at the end of my journey is the mother I needed to be at the beginning.....**

**Assertiveness skills and empowerment** – speaking up for ourselves effectively, presenting at meetings, communication and listening skills, learning to work in partnership

**Knowledge and awareness raising** – exposure to what is possible and how it has been achieved elsewhere.....Partners in Policymaking and In Control!

**Issue-specific training** – look at creating self-sustaining options. Pay carers to train other carers and don't leave us out of the training you give to staff who work with our children

**Advice, advocacy and brokerage** – someone independent to go to when things are tough

**Formal and informal support networks** – families supporting families through friendship, mentoring, and a listening ear

Working with parents and carers is  
**not** about consultation mechanisms,  
it is about creating a whole **cultural shift**

Empower us and we will work with you. See  
our experience as a strength.....

Look at how you can use us as a resource  
and let's start planning together.....

**“He looks at how it  
is and asks why?**



**I look at how it  
could be and ask  
why not?”**

Martin Luther King

# Thank You and Questions

***With thanks to J and T for sharing their stories***

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