

SMALL POWERFUL EVERYDAY THINGS

**CONVERSATIONS OF HUMANITY
IN THE SEND SYSTEM**

Welcome to **SMALL POWERFUL EVERYDAY THINGS**, a publication of 12 true stories told by special educational needs and disabilities (SEND) professionals, learners and their families.

Whilst the perspectives of our storytellers are vastly different, their stories reveal a unanimous goal: everyone within SEND wants to create a more supportive and humane system that places those most in need at its heart.

It is clear from these stories that systemic reform must happen at all levels in SEND, but there is also the hope that small powerful everyday actions of individuals can make positive change happen.

There are three sections to this publication to help SEND professionals use it as an effective tool:

Section 1) 12 stories from learners, parents, carers and professionals

Section 2) The small everyday things that happened when people shared their stories

Section 3) Ideas and tips on how to use storytelling to bring about change



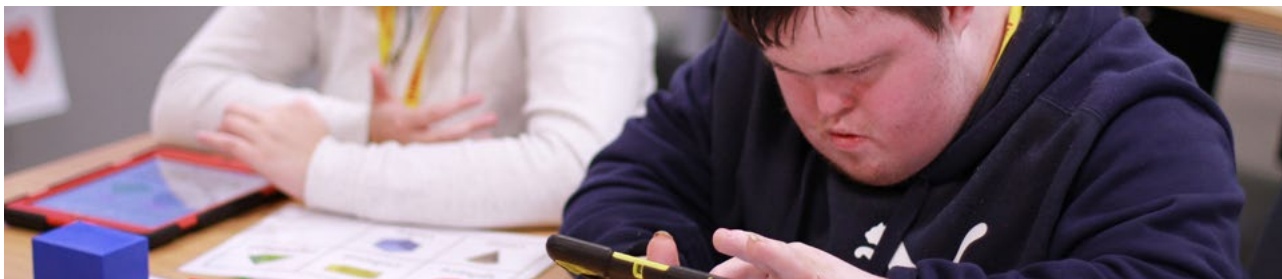
Why stories matter

The Education and Training Foundation (ETF) is committed to supporting effective practice within the SEND system. This qualitative publication provides a snapshot of the SEND system through the eyes of individuals within it. Through the storytelling of their experience, we hear of a system that is not always meeting learners and their families' needs, despite the many dedicated and caring professionals working alongside them to make the system better.

From these 12 stories, we hear how:

- 1** Some learners experience hurt, pain and exclusion when all they want is friendship, to learn and to have a future
- 2** Some parents/ carers find themselves exhausted by constant battle to get what their young people deserve
- 3** Some professionals often find themselves overwhelmed, exasperated and defensive

Through storytelling, people with different perspectives can come together and share their common humanity, hopes and goals. But, as we discovered, the act of telling stories, listening and being listened to in itself, has a positive impact on those working in SEND (as seen in Section Two).



The SEND system

The SEND system is defined as being about the organisations, people and processes that surround children and young people when they have special educational needs and disabilities. Key actors within the system include children and young people with SEND, parents and carers, and professionals which includes practitioners, managers, leaders and policy makers in education, health and social care.

From our conversations with these learners and their families, it has become clear that the SEND system is still not what it could be. In their experience, the system isn't always person-centred, caring or as humane as it could be, despite the good intentions of well-meaning people. It can seem process-driven, uncaring and confrontational.

The SEND system is made up of thousands of people – real human beings. It is not a 'machine' that can simply be fixed by some expert mechanic working from the top. Those with the most senior authority have much they can do, and we hope that positive changes will continue to happen. But it will take more than 'top down' approaches to really bring everyday change at the heart of how young people with special educational needs and disabilities are supported in their education, and beyond.

Everyone who is part of or touched by this human living system can choose to make a difference in any number of small everyday ways.

Why stories and not case studies?

These are stories, not case studies. A story is an account of events in a person's life. They own that story: it is personal to them. These stories are the truth for each story teller and offer no perspective other than their own. You will find out more about how you can gather your own stories in Section 3*.

This publication features 12 stories from learners, parents and professionals as we sought to explore whether equal voices deeply heard could help dismantle the barriers and tackle the challenges experienced by people and help heal the system one small bit at a time.

The approach of gathering and sharing personal stories was to provide space for people – learners, parents/carers and professionals to tell their story of their experience of the SEND system, and to listen deeply to those stories to see what change could come about.



How to use this publication: SEND professionals

We want everyone who works in the SEND and inclusion sector to read this publication to remind us all that no matter who we are, whether a learner, parent or professional, we want the system to work.

In Section Two, we have included what happened when people within this project told their stories. They demonstrate how stories create ripples that take us to places we don't necessarily expect.

In Section Three, there are ideas and tips on how you can create your own stories and use them to take action and bring about change. You can use this publication for your own personal reflection and commitment to act or use it with others for group discussion, and to encourage collective action.

Most of all, this publication aims to stir us all into action to do small powerful everyday things that makes the changes we want to see.

* For more information on the power of story telling and using personal narrative, check out our [How to lead when you're not in charge guide](#)



SECTION 1

12 STORIES FROM LEARNERS, PARENTS,
CARERS AND PROFESSIONALS

12 stories from learners, parents and carers and professionals, for you to read and questions to prompt reflection and discussion

The process of gathering the stories

Working with two colleges, we simply asked people if they knew people who might be willing to tell their story. We were looking for learners, parents and carers and staff. We easily found 12 people that represent a range of perspectives.

Those who accepted the invitation, told their story to our facilitator (Di Neale) in one to one conversations over the phone or video-conference.

The first drafts were then reflected back to the story teller by Di in the format that follows:

- The right hand side setting out the main points of the story told
- The top left box containing **the thing** that felt most meaningful or most important to the story teller
- The bottom left box containing some actual quotes – the voices and words of the story tellers

The process of going back to the story teller with each draft was key to maintaining ownership of the story. Each summary you see below has been approved by the story teller both in their wording and for use in learning, training and seeking to act to improve some of the issues raised.

Some names are real and used with the storyteller's consent, others have been changed by request.



Angela

I want to talk about the massive disparity in standards between education and care.



"Everyone talked about developmental delay, I thought that meant they would catch up."

"I feel so let down by the care system. I wish care could come up to the standards of education."

"The mental health of parents is often very fragile."

"Fighting for your own helps parents feel strong and resilient – it builds stamina and resilience. When you get clued up, you get empowered to deal with it – there are lots of ways to help yourself."

Before her twin boys were born, there were small signs that all was not well. Struggling with babies who would not feed easily, who were not meeting their milestones as normal, and trying to find out what was going on was tough. By the time the boys were 6 years old Angela was suffering from depression.

School support was really good and comprehensive, with good educational support, residential and respite support – she describes holidays as "horrendous".

Post education, and now 27; Ashley attends day care and lives at home with Angela. Jamie went to live in residential care, as his complex needs (autism, ADHD and mental health problems) mean he needs significant levels of support. The care system failed him. They took him off his medication, changed his routines and just didn't understand his needs. His brain couldn't cope and he became very distressed. He couldn't eat or sleep and he started attacking people. They evicted him without giving time for new arrangements to be put in place. Jamie was then sectioned under the Mental Health Act, and he spent 12 months in an Acute Treatment Unit.

Care staff are not trained or prepared to work effectively with people with complex needs – Jamie's current carer is 20 and has only worked at Nandos before this job. Angela believes that for cases like his, everyone should have a NVQ Level 3 qualification in Care. Angela said:



This is why I do the job I do as Family and Transition Support in a Specialist College. I understand where families are coming from, I understand the system and their situation.

I wish Care standards could come up to the level of Education.



Dave

We must support the staff the way they need to be supported as a key element of becoming an outstanding college.



"Working in the prison was enjoyable. I met a lot of young men who had been through the education system and been let down; through the care system and let down. I thought that if I could get in earlier, I could stop them going down this route."

"I really fell in love with the idea of behaviour – that if we could understand it and engage with it, then we could build trust and support learning."

"Whilst my physical presence is in management, my heart is very much in the classroom."

"Staff have 'who knows what' going on in their backgrounds and family lives and they put a smile on their faces and show up for work. If things go wrong they go wrong. We need to be asking what's happened, how can we help?"

"To be an outstanding college we need staff to be supported, who will stay because they know we care as much as they do."

Dave qualified as a music teacher in 2000, and went into secondary school teaching. The reality wasn't what he expected or wanted – spending more time dealing with behaviour than teaching. Changing schools led to things being better. "Five glorious years" during which Dave rose to be Head of Department.

In 2008, his daughter Evelyn was born. At about six months old, it was concluded that the most likely reason for Evelyn's severe disability was a rare genetic syndrome, passed through the male line. Dave was 'blamed' and, over time, excluded from his daughter's life. During this very difficult period Dave's marriage ended, he gave up his job and lost all his confidence. For a while was severely depressed, but thanks to the support of his family things started to improve.

Dave went back as a supply teacher, and then went into teaching in the prison service. From there, he got a job at a school for children with emotional and behavioural difficulties; followed by teaching children living in care homes who were victims of abuse or exploitation.

Joining a specialist further education college in 2020, he now focuses on Behaviour and Curriculum. As a manager he supports front line staff with their work, with helping resolve behaviour issues in the classroom.

He is very aware that staff, like parents and students, have complex lives. Particularly shown in the current pandemic when several members of the staff team have had significant difficulties, stresses and bereavements.



We need to show the staff the humanity we need them to show to our students.



Staff mustn't be seen as expendable or easily replaceable. A positive atmosphere for everyone is really important for staff, parents, students.

Dorothy

I want people to have understanding and training in the effects of trauma and adoption - how it impacts children and their families, particularly those with additional needs.



"The early experience for me was very hurtful, it destroyed my self confidence and self esteem. I was blamed as a bad parent."

"I asked for help and was refused. I was told it was part of the bonding... They put in safeguarding procedures instead of support."

"The whole time you are fighting, - a world war, not just little battles. You develop this....., you get hardened, it's absolutely exhausting."

"Once you get a diagnosis 'label' it helps."

"But then you are still fighting to get the resources the plan says you need. It feels like the system is trying not to give you what they recognise you need."

"I am not confident in the system and confidence and trust in who you are working with is a massive issue."

Dorothy is the mum of three adopted children with additional needs, including Eliza.

Dorothy's story of her experience told of her attempts to get support to understand and help her children. She was not given support, as she requested, either to support the bonding process or for suddenly being a parent to 3 children in their 4th fourth home. She was then told her parenting approach was to blame.

She undertook therapy with Eliza, and learned a lot about her daughter. Eliza got therapy to help her with her traumatic background prior to her adoption. Dorothy was eventually diagnosed with secondary PTSD as a result of the trauma of her experiences. Joint therapy enabled her and Eliza to build the foundations from which a very close relationship has been established and developed.

The therapy was through a specialist agency that fully understood adoption/trauma and was supportive rather than accusatory. Dorothy strongly believes that education facilities need to learn to work with specialists like this and take on board their recommendations to help these children and families.



The specialists are often not statutory services and here is the problem – 'cause this costs money in a climate where monies have to be prioritised to provide for the majority.



Through private routes, Dorothy got a diagnosis for Eliza relating to Foetal Alcohol Spectrum. Eliza finally got an EHCP.

Dorothy has mixed experiences of Eliza's schools, some were described as awful, others faultless. What made the difference was their knowledge of special needs, willingness to work closely with parents as a team, and willingness to give the child what they recognize they need by way of support.

Staff mustn't be seen as expendable or easily replaceable. A positive atmosphere for everyone is really important for staff, parents, students.

Eliza

Schools need to try to understand my need for extra support, with learning and with my emotions it isn't fair that my brothers got less help than me because they went to a school in another county.



"I knew things were getting better when I spent less time sitting outside the classroom and more time inside."

"The counselling support made a big difference for me and my mum and our relationship."

"One of my brothers had to move out, he vandalized the house, my mum now has PTSD and our family has had more disruption and trauma."

"My brothers didn't get the same support as me, even though they have similar issues, some of them worse, because they went to a school over the border in the next county."

Eliza was born in 2003. After leaving her birth parents, she lived in two foster placements in just 2 years before she and her two brothers moved in with the family who would soon adopt her.

She started at the local primary school in the small Devon village where she lived, but she was often angry and couldn't settle. She didn't think the school knew anything about how to help her. A new school and counselling (some of it with her mum), leading to 3-4 years of therapy helped her to understand her history with her birth family. Eliza got her own EHCP in primary school and got support in lessons, as well as a key worker for emotional support.

Bullying was often an issue – if you needed additional support you were a target for the bullies. She always struggled to make friends, but had a few good friends in secondary school.

Eliza went back to counselling in 2018 during a difficult period of time at home between her brother and her mum and dad.

In 2020, Eliza moved to college to study for a Level 2 Diploma in Early Years Practice. She worried a little about getting the support she needed at college, but that has all gone pretty well. When COVID is over she hopes to start her placement.

Frank

Having a diagnosis leads to people understanding me better, and I get to go to the places that I need to (like special schools).



"It was mostly ok but there were a lot of issues. I got into trouble a lot, I bit a teacher once - I just didn't really fit in."

"When I got diagnosed, I don't really remember how it felt, but things got way better after that."

"I went to a special needs school,.... A lot of things used to aggravate me, but that stopped happening when I got to my H*** M*** school. Things got better after that."

"I did a work placement at a Country Farm in 2016, and spent a week working on the farm, where they kept the animals. We cleaned them out, I had a good time. It gave me some ideas to think about work."

"When I went into 6th form, I had more freedom, was treated like an adult, I could go places by myself."

Frank is 20 and lives with his mum. He has a sister who is studying at university.

His first school was a mainstream one, and they didn't know then that he had autism. Frank tells of how he was "kicked out" when he was 4 or 5 years old. After a few months at home he went to a new school where he was diagnosed with autism.

He went to a different school, for children with special needs, and described how lots of things used to aggravate him back then. That school building was then demolished and Frank moved to a different site.

At age 11, he moved to a special needs secondary school. Frank described how this school helped him a lot – it was a good experience for him.

Moving into the 6th form was even better, he made new friends and enjoyed the extra freedom.

Frank passed 3 GCSE's: Maths, English and Art.

In 2019 he moved onto a specialist Further Education college. The move went smoothly but was difficult, with Frank saying how much he still missed some of the people from the times at his previous school.

At college he is learning about gardening and cooking, but due to the COVID pandemic, he currently does more paperwork at the moment.

Kelon

Having someone in the school to keep in touch with, who will tell me when we need to change something, who came with me when we visited colleges.



"It's tough, but you've gotta cope with it."

"It made a big difference to me that Maggie from the school came round the colleges with us, and helped us find the one that would suit my son best."

"Angela is someone I can go to if I have questions, I stay in touch with how things are with her."

"He is happier at this college, it is a calmer environment – the other colleges were not calm enough for him."

Kelon is the mum of three children, two of whom have additional needs. Her son Ilyas is 21, has ASD, epilepsy and is non-verbal. His behaviour can be difficult as he doesn't sleep well.

Starting off in mainstream school, it was clear by the time he was 4 that a special needs school would better suit his needs.

The school has always told Kelon when they believed Ilyas needed more help.

When it was time to leave secondary school, one of the teachers arranged to visit colleges with Kelon and another mum, so they could try and choose a college that would best suit her son – they visited three and chose the one that would best suit him.

Now, Kelon stays in touch with the college through Angela. She knows that her son is happy and making progress with his programme of learning and skills.

Laura

We need more input from the different agencies in supporting students: Social Care, Health, and Mental Health; so the EHCP can be what was intended. We need more support for young people on mental health and mental wellbeing.



"In 1997 there was plenty of money around – if you needed something for your students, you just had to ask and you got it."

"I think EHCPs are a marvellous idea. But the reality is that 90% of the support and resources come from education. Only very rare cases get any support or input from social care or health."

"At the end of college life there is a bit of a hole for those students who probably won't be employable. Particularly with the reduction in social care, day services and other options are not what they used to be."

"The reality is there are few options to refer students on to for mental health support."

"I am hugely proud of what we achieve here for students with identified needs. We change their lives for the better."

Laura began working with young people with physical disabilities as evening work after having her children. This led her into work as a Learning Support Assistant (LSA) in a mainstream FE college. Starting as one of around 25 LSAs, she moved on to manage them, there are now around 75.

Since 1997 when Laura joined the college, the number of students with an identified need, and an Education and Health Plan has increased massively. The rise in the age of participation in full time education, the right to go to college, and the Disability Discrimination Act has opened up Further Education to more students with disabilities.



We started with only one or two students with an EHCP, now there are over 300.



In college, the SEND team have overall responsibility but there is sometimes a challenge getting colleagues across the college to implement the adjustments that the plan sets out as needed – "some are brilliant at it, others less so".

The main thing I think needs to change is that we really need to have more input from the full range of different agencies. We very rarely have any input from Social Care, Health or Mental Health services. When young people are in distress, worrying about their mental wellbeing, gender identity issues, stress and anxiety leading to thoughts of self harming; it is almost impossible to get specialist help. We support people as much as we can, and we have some student counsellors but the whole point of the EHCP was that complete package of support.

Looking after young people's mental health makes very good economic sense, as well as being the right thing to do.

Leah

It is important that people know about me. Having nice people around makes a difference.



"It was terrible" "I struggled and they said there was nothing wrong with me" "I couldn't get the work right" "But I knew there was – and I needed the support that I didn't get."

"I thought the people were nice, but they started bullying me for no reason."

"I had a TA who was helping me, she sat next to me."

"I had more friends at that school – they understood what was wrong with me. It was just a happier place."

"They found out that I also had ADHD and that meant I had learning difficulties and it made sense, because I knew what was going on and why I was struggling, so I felt much better."

Leah is 20 and lives at home with her mum and nephew.

She struggled at her first primary school, with work and making friends. Her mum moved her to another school where they discovered she had Autism. Things improved after that – she had a teaching assistant who helped her with more suitable work. It was a happy place and she had more friends.

Moving to secondary school saw things get difficult again. Leah experienced bullying from girls she thought were her friends.

In year nine, Leah moved to a special school. She got a EHCP; was diagnosed with ADHD – so why she had difficulties with learning made more sense to her. Leah was happy at her special school, although sitting in silence in the exams was hard.

Leah's story included lots of things that made her happy: her nephew, brother and sister being born; going to the prom at her 6th form, and her work experience at a farm. Having friends and not being bullied are also really important.

At college she is learning about independent living, travel training and employment experience. Leah has struggled for a long time using public transport because of her anxiety.

Levi

It would have been much easier if the diagnosis of autism had happened earlier, then the years of struggling with the work needn't have happened.



"I hated school because I struggled, they wanted to put me back a year."

(of his autism school) "It was like a normal school, but with lots of help. I improved a lot."

"At college I have an annual review of the support I get, and how it is all going for me."

Levi is 20 years old, and lives with his family, 4 dogs and 1 cat in a village near Barnstaple.

Levi changed primary school in Year 4 because his family moved house.

In Year 5 it was discovered he was autistic. Levi had been getting help with speech and language, but it was felt that he needed one to one support, which wasn't available unless he was assessed to need it. That assessment led to the autism diagnosis.

In Year 7, Levi went to a specialist autism school. It was very small (fewer than 100 students) which suited him really well. He progressed really well, and enjoyed school much more than before.

In Year 10 Levi choose from a range of options including construction and mechanics.

After secondary school, Levi moved onto college. At the interview he was asked if he wanted additional support. The first year included learning about college life, Maths and English, Cooking and Mechanics. With support over time, Levi has been getting used to being in bigger groups of people; something he finds difficult.

He has passed his GCSE in Maths and is studying for his GCSE in English, which he finds harder. In his second year at college he did courses in Furniture Making and is now doing a Level 2 in Painting and Decorating. He hopes the college will offer him a Level 3 in Painting and Decorating, but that is still to be decided. For the future he is thinking about an apprenticeship in Painting and Decorating.

He would love to become a furniture maker, but knows it would probably be more difficult to find an apprenticeship and a job "there is so much flat pack furniture"

Lindsay

I believe that we need to attend to staff support and wellbeing, as part of a 'Governor to learner' culture that sees us all acting with shared purpose, ambitions and expectations.



"I always used to say that I was undiagnosed ADHD. Because at school I didn't know that I could achieve 'Distinctions' if I sat down and learnt how to concentrate."

"Working in prisons I was very happy. I was interested in what I could bring to it and to the people I was working with. I learned more about myself from learners I taught in prison than from anyone else before."

"In the four years since my bereavements, I have become much more focused on supporting people, on meeting people at a level of human connection that is different than before."

"My intention to help comes from my place of grief – we're only here once and let's really try to understand each other. But there is sometimes a deep mistrust."

"COVID has had a huge impact on staff. It's about supporting people through life, especially when people have lost others."

Now a Principal of a college, Lindsay hated school, apart from Art and other practical subjects she found little of interest to her and she couldn't concentrate. Leaving with just enough qualifications to go to University, she had no idea what her potential was.

14 years later, Lindsay went back to University again. She feared how hard it would be after her earlier learning experiences; but found herself excelling, much to her amazement. She trained as a teacher, focusing on ESOL and literacy.



I got really interested in how people operate, and how our brains work.



A five week trip to Australia in 2008 gave Lindsay space to think about what she really wanted to do. After previously working with the long term unemployed she went into teaching in prisons. Lindsay learned a huge amount about how to support and bring out the best in people, how to understand them and really listen to where they are coming from. She became a 'curriculum trouble-shooter' and an advocate for supporting learners with a diverse range of needs in a range of new or struggling prisons.

In 2016, Lindsay was hit by a series of bereavements of family and friends: losing someone every month for six consecutive months. She took 3 months off work to try and process what had happened to her, started to sink, but got some support and started to pull herself back. Lindsay's grief and loss changed several things for her. It strengthened her focus on supporting people and being committed to their wellbeing, gave her an understanding of emotional intelligence, and cemented the importance of celebrating what is going well as key to bringing out the full potential in people.

As College Principal, Lindsay was extremely proud to be part of achieving the GOOD Ofsted judgement, a college restructure and being part of ambitious plans for the future. But the many months of COVID have been hard for everyone, and brought back into sharp relief the need to support people going through tough times. Times have revealed some tensions and differences of view. Sometimes, attempts to support people feel mistrusted. Lindsay reflected that it might be a good time to discuss and clarify, for everyone, our history, purpose, ambitions and expectations, and consider how to develop the culture that 'Governor to learner' we need to have to be successful in the next phase of the story of the college.

Mim

I want us to develop a new approach to meeting the needs of all students with a college-wide system and language of inclusivity.



“I thought everyone was just randomly different.”

“We define people by their differences and it's a shame.”

“I want to get rid of all the separateness we have at college, so all staff can be confident talking to any learner about any issue, about how life works for them, whether they want some support, and how we might help.”

“I get ‘first contact’ emails set out in legal terms, clearly written with a solicitor's advice; talking about negligence, about students I have never previously had a conversation with or about.”

“I am very, very proud of what we do here. If our students leave with nothing else, I want them to leave being able to state their opinions and their preference.”

Mim was born into a residential home for babies, children, young people that her parents ran. She grew up thinking that everyone was just randomly different – different colours, personalities, temperaments and physical traits – and everyone was equally included. Complexity of need was never discussed, just accepted. “I thought everyone was just randomly different”

In her early career she worked in a semi-secure residential unit; finding the work challenging for her mainly because the boundaries were blurred between being teacher, care-giver, adviser, house-sharer. Working in schools, Mim felt like she was expected to ‘tow the line’. Despite having a teaching qualification, the strong and prevailing sense of hierarchy left her feeling constantly undermined by the teaching staff.

Now working as the SEND lead in a large FE college with around 10,000 students, Mim is responsible for SEND reforms and statutory plans (EHCP). 9% of students have EHCP's – and 91% don't, but emphasises that it doesn't mean the 91% don't have needs for individual attention and support from time to time. Money and time is focused on those with a statutory plan.

“When I first started work here, I would worry going into a meeting about being able to call to mind the current ‘correct’ terms for various diagnoses or conditions.”



I want the whole college to be a Centre of Excellence for everyone. The language of special needs defines people as different from those without special needs - it feels old-fashioned and discriminatory. I want us to change to a language of inclusivity across the College.



It is sad that the system is becoming increasingly legalized. The prevailing language is of statutory plans and legal rights. “We increasingly focus risk assessments in anticipation of the court cases that will come. I spend more time supporting parents than learners, and sometimes the learners don't want what has been decided for them – I feel so much of that is wrong.”

It's been really tough with COVID. There are students who arrived last year, and students planning to join us this year who I haven't even met yet. We have tried really hard to respond to what students want to do during this difficult time – we opened up the campus for one student because ‘he had the right to come’. We took the request very seriously, put everything in place, the full range of support needed. We made it clear he would be the only student there, but after just one day it was clear that being alone wasn't what he wanted – so he studied at home after that.

I want us to keep sight of how we can be for all learners. I am interested in a system of inclusivity.

Sally

Never give up on the end goal, however long it takes. Passionate, empathetic, positive and motivated staff working in sync to support the Learners to reach their full potential.



"The consultant told me "she'll never be an athlete, but that's not to say she won't be a mathematician."

"I did some crazy mad things with the A. I didn't accept there weren't things we could do, and I knew that the more we helped early on the better."

"It takes a lot of time for me to trust people."

"The first 2 years were very difficult at the College, a horrific Ofsted journey; but between 2016 and 2019 we went from 'Inadequate' to 'Good'. We fully intend to achieve 'Outstanding'."

"With the College Principal we have built a strong and close relationship, and are working hard to find our way forward. As we grow, we have got new managers in to support the running of the services, and we all have to learn to work differently together to find the ways that work. I have to learn to put a zipper on it..."

Amy was born 7 weeks early, but it took two and a half years, and a change of hospital to get someone to understand that something was not right.



The worst part is when you do get a diagnosis. You have to absorb it. Amy was my first child, and you go through the grieving process for the child you thought you should have had. You can either get over it and turn it into a positive and go into fight mode – this is the situation, what am I going to do about it?



From my background in Early Years, I knew that early intervention in brain development was everything - the more you put in, the more you might get out. We took her for Hyperbaric Oxygen Therapy, and did programmes connected with the British Institute for Brain Injured Children – they both made a huge difference for Amy.

We were lucky to have some really good people around us that we built relationships up with over very many years. The GP is amazing (I am dreading when she retires) and two fantastic paediatric consultants. We have had some truly awful experiences too – surgeries that were an absolute disaster where the care was terrible. There were tough times, but I have a close and supportive family, which helps. Trusting people is hard to get your head around when situations like that happens.

I was involved in parents groups, and met a lady who would become my mentor and friend. I got involved in groups on the Council, involving parents in designing services for children with SEND. I knew there were gaps coming up for Amy. If she wanted to go to college at 18, there was nowhere locally for her. She would have to go away for three years on a very expensive out of area placement, and when she came back would have no local connections. I didn't want to send her away. So with another set of parents, we founded a Specialist College; and with the relationships and professional contacts I had made on the strategic groups we opened the doors of the college with an email saying the City would support us.

My focus now is to continue to build the services. My end goal always was a village – with housing, a community, connected to a local community. So we are looking now for a place to start doing some overnight stays, allowing people to learn to transition away from home. We've had some set-backs recently, but that continues to be the goal.



SECTION 2

SMALL POWERFUL EVERYDAY THINGS
THAT LEAD TO CHANGE

The small powerful everyday things that happened when people shared their stories

When we were going through the process of telling and collecting stories, it was immediately apparent that it was having an impact. Small powerful everyday things were happening. We share them here because they demonstrate how stories create ripples that take us to places we didn't necessarily expect.

These are some of the small powerful everyday changes that people within the project made. They came from conversations about the impact that story telling had in their workplaces. We haven't attributed the comments because they were confidential honest conversations.

Being more self-reflective

Telling their story and having it 'given' back to them sparked people to reflect on why their journey had brought them to the place that they were now at. They talked about 'taking a step back' and 'finding quiet moments to think about it' and to ask themselves 'Why am I doing this job?', 'Why is it so important to me?'

This then enabled them to re-focus on what mattered in their jobs. One staff member said:

“ I was sitting in front of my computer all day, everyday, dealing with emails and forms that never seemed to stop, and I was losing it. It felt like one of those computer games where more and more things come at you quicker and quicker. Doing this made me step away from it and re-focus’.

Reflecting and re-focusing impact on wellbeing but also on motivation. One staff member said:

“ It just made me want to do it better, to keep going.’

For learners, telling and hearing stories of others, including staff and parents made them reflect that 'we're not so different from each other'.



Changes to practice

Working with parents. Staff reported that they changed the way they interacted with parents, starting to listen to parents and giving parents more space to say what mattered to them, instead of rushing to 'helpful', problem-solving mode. One manager said:

“ ‘I was interviewing a parent of a prospective learner. Usually it’s about what we do, what forms have to be completed and it becomes a meeting of demands with ‘you’ve got to do this’, and it leads to lobbying and complaining. But now I just put my pen down and asked how it is for them and what matters, and it feels so different’.

Another manager said:

“ ‘I was showing a father around of a girl who may come to our college. Usually I go into ‘this is what we do on the curriculum mode’ and it’s all about filling a place. I didn’t do that, and he began to talk about how the girl’s mother had died six years ago and he had been a single parent since, how that had been a struggle. I don’t know whether she will come here, but if she does, I feel we will know so much more about her and what is important for her and her father’.

Both colleges are now exploring how they work and support parents, and how they can bring parents together to support each other.

Working with learners. Hearing the stories of learners made them see learners in a completely different light. One staff member said:

“ ‘We had a learner whose behaviour was causing some major safeguarding concerns. But when we heard her story, it suddenly dawned on us ‘that’s why she is doing what she’s doing!’ and it has totally de-escalated the situation and we are working with her in a different more positive way now.’

Challenging EHCPs. While the staff had often doubted or dismissed the content of EHCPs as being out of date and not learner-centred, hearing the stories told by learners made them challenge the content of EHCPs as being in some cases inappropriate and disrespectful to the learner, and try to present a more positive, respectful and age-appropriate view of the learner.

Changing strategy. Following a period of reflection and re-focus, the SEND managers both changed their strategy documents for their area of work. One manager said:

“ ‘It just occurred to me that a strategy doesn’t have to have all the right buzz words in it, it just has to be about what really needs to be done. It made me think about how am I going to say that in a meaningful way and how do I influence others to work with me and work together.’

Changes to organisational culture and staff wellbeing

Both SEND managers used the story telling activities with staff hoping that staff would get to know each other better and to build positive relationships. This led to staff being more open with each other, more aware of when colleagues might be struggling and more ready to ask and listen.

Staff themselves were more aware of what they might be bringing to work and how it might be affecting them. Rather than internalising those feelings negatively, they were able to be more objective and see what triggers them emotionally. The story telling activity seemed to foster a kinder, more humane culture at work.

This kindness manifested in other small but significant ways:

“ ‘I always used to say thank you to people, but now I say why I am saying thank you. It seems to make my thank you more important to people.’

“ ‘When there are niggling problems in the staff team and people are getting tense and agitated, instead of rushing in to sort it out and direct people, I take time to ask what is going on, what is upsetting people and I listen. Most times I don't have to sort anything out, it sorts itself out. They just want someone to listen half the time.’

“ ‘Conversations had always been about what is going wrong all the time. It's completely changed the conversation, it's more positive and people give more feedback to each other.’

“ ‘I always watch my language now and try to use positive language.’

“ ‘I invest more time in people. I thought it would add to my work but I have found that investing a few minutes with people has had more of an impact. I've got my time back in other ways. Problems don't build up. And I don't think there is so much sickness absence.’



Finding a voice

Telling their story seemed to help people find their voice.

“Learners said ‘my story matters. I want to be able to tell it.’ and ‘I think if I can tell my story I can help others.’

Staff reflected that it wasn't just the telling of the story, they also learnt something about how to tell a story in order to be heard

“I have a lot going on and I'm not always happy at work because of that. When I tried to talk about it in the past my voice got shaky and I rambled and rushed to get everything out. I didn't get what I wanted to say across, maybe I was confusing. But telling my story and then reading it back with ‘the thing’, made me realise that I could be clearer, take my time and plan it. Not just bottle it up and then gush it all out.’

It made people think about how authentic they were in their roles.

“I think I had an image in my head about how I should act professionally – efficient, expert, knowing what to do all the time, you know, maybe a bit detached. But really, I'm not like that, I think I want to be more me, more real. Yeah, I know my job but I want to be me.’





SECTION 3

IDEAS ON HOW YOU MIGHT INITIATE
STORIES TO HELP CREATE CHANGE

Ideas and tips on how you can create your own stories and use them take action and bring about change

In this section we want to give you a few ideas about working with stories. We hope that reading this far has led you to want to give it a go. First we will talk about using the stories in this publication, and then about surfacing and working with other stories.

We believe that working well with stories allows us to access much more than the 'facts of the case'. They ask us to deeply listen with our whole selves; to see if we can hear beyond what we might be listening for; to come into a relationship of humanity with people. And of course there is, in each of our twelve stories 'the thing' that mattered to each story teller.

There are many reasons to and ways of working with stories to improve experiences and services. In this piece of work, the key was that we wanted to enable the story tellers to tell the story as they wished to, and through that to point to why it was important to them to tell it. For example, Dave and Lindsay both wanted more attention to be given to staff's care and welfare; Angela wished to change the quality of adult social care for those young people with significant disabilities who transition out of education at age 25. We hope there is more change to come by those inspired to talk together about these stories, and in helping people to find and tell their own stories.

You might wish to use the stories in relation to work you are doing to improve services or relationships with other parts of the system – helping to focus on the real experience of people, in their own words. You may want to bring new life to the core value and commitment to listen to learners, families, carers and staff.



What do we mean by 'listen deeply'?

Often when we listen, particularly in our busy professional lives, we do so to respond. We are self-oriented (what do I..) and re-active (need to do about this?). Deep listening is to be open-minded, genuinely interested in what is being said, providing time and space to fully absorb what is being said. It encourages other to feel heard and to speak more honestly and openly.

When we listen deeply we are not there to be helpful, problem-solve, commiserate or evaluate. When we deeply listen we are there to be generous with our time, be empathic and caring to the other person. We don't necessarily have to agree with what we have heard, but we must acknowledge that what the other person is saying is their truth.

Working with these stories

Try this:

- **Assemble a small group of colleagues to 'try something a bit different'**. It's fine to be low-key about it. Doing something for the first time can be a little daunting, so why not just say we're going to give something new a try, just to see how it goes – it takes the pressure off a little bit. We believe there is insight and learning to be had from whatever happens. Let's face it – we have all spent hours in meetings that can sometimes feel a little less than inspiring, so doing something different might be a refreshing offer. You might also simply ask people to read this whole publication and then come together to discuss it. You can do this in face to face, or on a platform such as Zoom that allows you to set up breakout rooms for smaller group discussions.
- **Give a short introduction to how the stories came about** (see the section just before the stories can help). Here it feels important to emphasise that these are the stories people wanted to tell. They are not case studies. The stories are gifts given by people who hoped their experiences might make a difference to others. It can be helpful to set a few ground rules, such as honouring the experiences by accepting the stories as told by the story tellers.
- **Allow time for colleagues to read a few of the stories.** You might ask people to read all the stories before they come along, or it can be very powerful to have a silent ten minutes while we all take time to read.
- **Break into pairs or small groups.** Take it in turns to talk about a story that touched you:
 - What did it make you think?
 - How did it make you feel?
 - What did it make you want to do / an action you want to take?
- Come back together as a whole group and **discuss the themes** that emerged from the earlier conversations. If people disagree on issues, or didn't like the stories – just notice what people are saying and move on. You might reiterate that the stories in this publication were gathered for no other reason than to be told and heard. We think that usually when people are asked to tell their story (for example in an EHCP) there are consequences, or it is part of a bigger set of discussions about their situation or case. These stories are true for the storyteller.
- Finally, **reflect on the session** you have just had. What worked well for people, what might have been even better, what would we change if we were to do something similar again?
- Thank everyone for their time and participation.

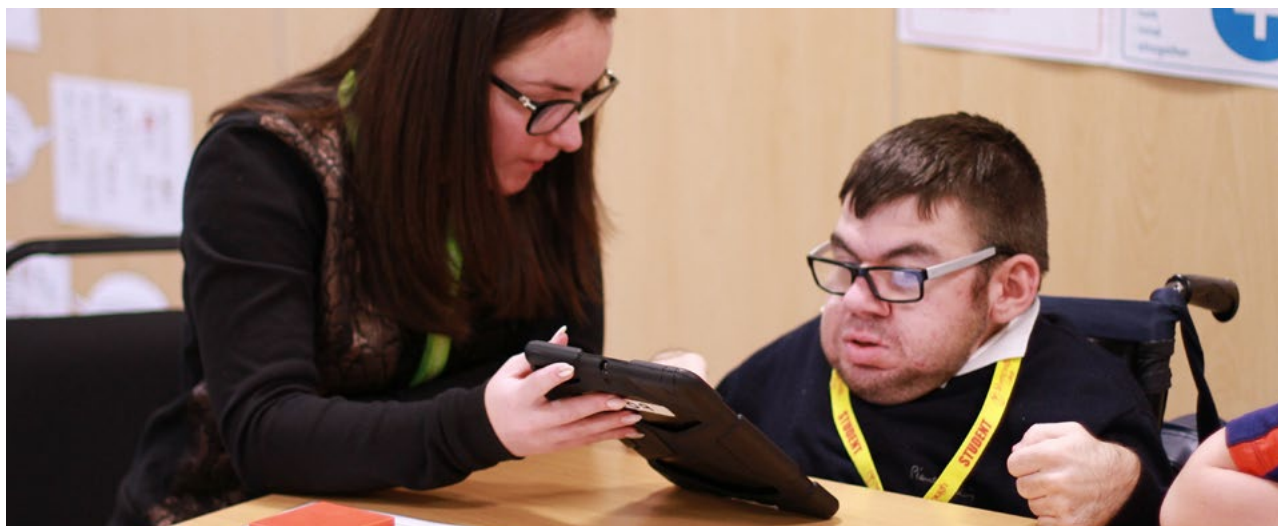


Helping people to find their own stories

We have already said a little about how we went about gathering the stories told here. But there are many ways in which you can work with stories. What is really important is your intention and being clear with potential storytellers about what you are trying to do, how and why. Stories are different from case studies or consultation. Each have their place.

In the short space available here we cannot cover the many ways that you might gather and work with stories. You can work with stories gathered from your own colleagues, your learners and their families, or people working in your local area or place; and use them to improve the way things are in relation to services, ways of working, experiences and relationships.

It's okay to have a specific reason for asking people to tell their stories, such as a problem or issue you are thinking about, but if consultation is what you would usually do in that space, you need to consider how honestly you are really wanting to hear the whole story that people might want to tell you. Storytelling is not a replacement for other communication or consultation methods – you would soon lose trust if your story tellers felt that there was another agenda.



Taking a trauma-informed approach

Telling your story should be a safe and positive experience. Sometimes people may talk about trauma that has happened to them or in telling or hearing a story a past trauma may re-surface.

Consider the following things before you start a story telling activity.

- Reassure people that they choose what they want to share, they do not have to share anything they don't feel ready to share.
- Reassure people that whatever people share is their truth and they will not be judged on it.
- Let people know that whatever is shared is confidential, but if an issue raises safeguarding concerns, it will need to be dealt with.
- Listening to the trauma of others can cause trauma for the listener. Ensure you provide support for that.
- Prepare yourself beforehand with information

Try to be clear why you are asking someone to tell their story, how it would be used, and what control they will have over it. For example, we committed to the process set out in Section 1, and gained agreement from everyone featured that they were happy for their story to be used in training and development to help improve the SEND system. Some people wished to be anonymous, which of course we have agreed to.

We used a specific methodology for the stories here. It took time and was quite time intensive in places. What is most important is that you find the best way to make sure that you capture what people actually say, not what you think they might have meant, or your interpretation of it.

People often need a little time to find their story. We don't usually move through the world with our stories on our sleeve, so asking a few open questions about important moments, or big decisions might be really helpful in supporting people to find the story they want to tell. It may take more than one conversation.

People writing their own story themselves, or telling it out loud might be a good way to start. If you then decide that you want to capture and share the story more widely you can work together to make sure it is well captured and your story teller is happy with it.

For us, the format we have written the stories into emerged from this stage of trying to write it down for sharing in this publication. What seemed important was: the story the storyteller told, some of the actual words used (the quotes) which give real power to the text, and 'the thing' – the reason for telling the story, the issue that each story teller hoped their story would contribute to addressing. The format for your stories might be different.

If you decide that the stories you are gathering, collecting and telling will likely endure beyond a particular session or piece of work, it is a good idea to agree (in advance if possible) whether people are happy for their story to go out into a wider world, and whether they wish to be named or anonymous.

Finally, ask how they found the experience, and what might have made it even better for them. There is always learning to be had when we look for it.

Telling and working with stories can be a very powerful experience, so both giving space for that as well as bringing those insights into the work you are doing is important not to miss. In the appendix below you can see reflections from our project team on being involved in this work.



Our call to action

The SEND system presents us all with many challenges and that was sufficient enough reason to do this piece of work, and the global pandemic has given us even greater cause.

The COVID pandemic has highlighted for all of us how vulnerable we all are and made us think about what is important in life. This project, undertaken during the pandemic when none of us could meet face-to-face showed us that stories, simply told and deeply listened to, provide us with strength and peace in the small powerful everyday things we can do for each other. We all have the power to make change happen.

We hope that you use stories now in your work and life, and that it spurs you to action to:

- Take time with each other, and don't just battle through to what you think is the solution.
- Listen well to each other, and not just wait your turn to say your piece.
- Be kind to people knowing that they are the experts of their own lives.
- Be kind to yourself knowing that it helps us be our best self.

Finally, we want to thank the learners, parents/carers and staff at Petroc College and Trinity College for their time, honesty and enthusiasm in their involvement in this project. This project would not have happened with them.





APPENDIX

SOME REFLECTIONS ON THE PROCESS

Four reflections from the project team about what the project threw up for them about the systemic challenges we face in the sector

Throughout this project, reflection was very important to us. At the heart of the stories we were asking people to reflect on their experience and on what mattered to them. This both gave the stories a depth and led to significant changes for some of our story tellers in how they saw themselves and their stories; and how they might tell their story in the future.

We have included them because they add another dimension to the telling of stories and might resonate and trigger your own reflections.

The following four reflections are from our Project Team: Lindsay Harris, Mim White, Kathryn James, and Di Neale.



Lindsay's reflections

It was strange sharing my story within a work capacity.

I spent the last four years 'getting on with it' and 'putting my work act on'. My career and life journey were two very separate thoughts that were stored in different parts of my brain. I knew my story often impacted on me at work but refused to acknowledge it. My thoughts held me back to the point where I felt suffocated and restricted but as I told my tale I noticed that it gave permission for others to breathe and become free of their own barriers. I began to make connections between the individuals I knew and their behaviours or thoughts. Situations made a lot more sense. I was full of emotion and shock at the thought of what people had been through, how others had been so unkind to them and how people perceived themselves in such a negative way.

Since reading the stories, I have changed both my approach and working practice. I acknowledge staff, learners and their parents or carers personal journeys before anything else especially during our initial meeting. I hear their stories and don't just listen to the words, I feel their emotion too. I think this has helped with forming respect and building rapport along with drawing out the best in people as it gives them the space to talk. People have then shared their most vulnerable side and if this is supported, it seems they turn out to be the most resilient. There have been tears during staff interviews, expressions of extreme gratitude from families because someone listened to them and deeper, honest conversations after implementing 'sharing stories' as part of our first full staff meeting this year. If this is the result of listening to people then stories should become mandatory practice in our everyday work life.

Mim's reflections

I found the words and stories that related to me most were those of the staff and parents.

These, in my role, are heard less. I heard the frustration and the protective pain from parents and also from staff who, despite it being their job, are emotionally involved and face barriers in their professional role. I had separated my role as a parent from my professional role.

In listening to the stories of other parents I realised that I have never been asked my story or been heard as a parent of a young person with an EHCP and neither has my husband. I think this has had an unintended impact of this experience for me. In my professional role now, I involve parents as much as possible (as appropriate in FE) and I listen properly to their story. And I have heard time and time again parents/carers saying how they don't feel that anyone is really listening to them, as we learnt to listen, is distinct from hearing their views.

What I have found is that the agenda that parents can be seen to present dissipates when there is time to listen and learn and that a successful outcome can be; simply having been listened to. I have also learnt that stories come with their own bias of their author and influences which is why listening can sometimes be enough without comment or action.

Young people were keen to share their views and seem relatively used to doing so, whereas parents found this more difficult. Two of the parents that I asked to be part of the journey did not feel able to do so as they felt that they would become too vulnerable and that they were not in a place to do so, suggesting the emotional impact of telling their story was not conducive to keeping everything going as a parent. I was struck with the parent that introduced themselves to the presentation sharing forum as 'I'm just a parent'.

I wonder if I see parents' views as predominantly difficult within SEND and hence why there has been a previous tendency to avoid them. Maybe this is the feeling that parents get in SEND, that they are seen as difficult too. This would be a shame, and this is the main thing that I have taken from this experience, investing time in listening to views without my own agenda, without making notes and without fitting these views into boxes to submit within a specified deadline.

Kathryn's reflections

When I read the stories and observed or listened to other people's reflections about the stories, the one thing that really struck me was the importance of deeply listening.

And when I say listening I also mean reading the stories – listening with our eyes if you like. How often do we listen waiting to have our turn to talk, or listen just to solve the other persons problem, sort a situation and get the job done quickly? Rarely it seems to me that we listen just to hear the meaning and emotion behind the words, and to listen with our whole bodies.

While we may acknowledge the tightness in our chests or tears welling up in our eyes when someone tells us something sad, how often, if we are totally honest with ourselves, do we acknowledge the sigh of exasperation, or tiredness or the knot of anxiety in our stomachs. Or read a case study thinking 'oh yeah, I've heard this before'. And then how often do we ask ourselves why do I feel like this? What is going on for me that is going to affect how I respond to this person? I'm saying all this because I have to hold my hand up and say I know I have done it, I have been too quick to move someone on, to ready to think I know what to do here, too tired, too over-worked and sometimes too sad to be able to care enough for someone else.

I was really touched by Dave and Lindsay's stories because they helped me understand why it is important to show up at work as yourself, and that means being honest with ourselves, acknowledging our own feelings, deal with them and take care of ourselves and others so that we are free to care.

It seems to me that if we are going to bring back some humanity into the SEND system then we need to start really listening to each other.

It seems we all work at such a pace, with so many constraints and stress that we ignore those feelings within ourselves, push them down just to get another task done and a job off our desks. While that is understandable when people are under such pressure, I wonder if it doesn't solve anything and just creates more hurt and more work in the end.

Di's reflections

Every story touched me – but two I would point to for different reasons.

Leah's story reminded me of a time when I was at school. A new girl came to the school – who we might now describe as having learning disabilities. I was asked to look after her until she got used to how things worked. I am a little ashamed to look back and remember how I felt. I was embarrassed, and irritated – we had nothing to talk about. I think about it now with sadness. I could have been kinder, more understanding, I could have chosen not to care what my friends might say, as I was helping someone who was finding life a little difficult in that moment.

Angela's story touched me deeply. Her twin boys were born in the same year as my daughter. Both our lives changed in that moment – mine changed as I had expected it to as a new mum; Angela's changed in a very different way from what she expected. I am in awe of the women I spoke to who are mothers to children with disabilities; and I am reminded that there is absolutely no reason I know why my life took the path it did, and Angela's took a different path.

The best way to honour the stories and experiences of our story tellers is to show up as yourself – your whole self. To be open to feeling the feelings the stories evoke, even if we're not very proud of them – which was my experience. Leah's story took me to a feeling of shame, Angela's story caused me to feel deep gratitude that my life did not take the same path as hers – I'm not convinced I would have been as resilient as her.

When we go to work every day, we have a professional identity – we put on a hat, we wear this identity and no other. We have read so many case studies – been there, seen that; we let them pass us by. At our story telling workshop as part of the work, it was clear to me as facilitator that people found it hard showing up as themselves, and taking off their professional identity to really hear the life experiences these stories speak about.

As you read the stories, I urge you to try and make the space and the time to allow them to touch you – not just as a professional, but as a mum or dad, son or daughter, friend, neighbour. This is how we build our shared humanity.

OUR PARTNERS



THANK YOU

157–197 Buckingham Palace Road,
London SW1W 9SP

020 3740 8280
enquiries@etfoundation.co.uk
ETFOUNDATION.CO.UK

Company registration number (England and
Wales): 08540597. Charity number: 1153859