



Tailor Ed

10 Year Anniversary Report

Tailor Ed Foundation was first set up in 2009 and recently celebrated its 10th year of operation. This report, completed in January 2021, is an opportunity to take stock, reflect on the progress that has been made since those early years, and celebrate the many successes that the organisation has had. We are grateful to all those staff and board members, and families who have contributed to the research that informed this report. Their stories about the impact of Tailor Ed's support bring the report to life.

Contents

Chapter	Page
1 Context and Service Delivery Model	1
2 Reach and Impact	6
3 Challenges and Opportunities	18
APPENDIX 1 Case Studies	22

Context

The National Autistic Society estimates that there are over 700,000 people on the autism spectrum in the UK and a recent research report published by the Scottish Government estimates that 5,249 people in the City of Edinburgh have Autism Spectrum Disorder[1].

In addition, the Scottish Government collects and publishes data on the number of pupils in Scotland who receive support for Autism Spectrum Disorder through the Scottish Pupil Census. According to the Scottish Pupil Census 2018, 1,171 pupils from primary, secondary and special schools in the City of Edinburgh received support for Autism Spectrum Disorder[2].

History of the Tailor Ed Foundation

Tailor Ed Foundation was set up by Dr Ruth Philip PhD (known to all as Roo). She continues to lead the organisation to this day, supported by a Board and staff team. Many of those involved today have been with the organisation since its early days, and this is a marker of the level of investment that the staff and Board members have in the organisation.

Following an undergraduate degree and a Masters in Neuroscience, Roo undertook a PhD investigating emotion processing in Autism Spectrum Disorder and as part of that work immersed herself in autism research. In addition, she volunteered at a charity supporting autistic adults and worked as a Behaviour Analyst with two young boys with autism.

All these experiences led to Roo, in discussion with others, setting up Tailor Ed Foundation to address a gap in support for young people with autism to provide them with support to gain everyday skills related to issues like communication, eating, brushing their teeth, getting their hair cut and morning and bedtime routines. These skills, if lacking, can have a detrimental impact on the whole family. Their mission and vision, developed then and set out below, remain at the heart of the organisation's work ten years on.



**Dr Ruth Philip PhD (Roo),
Founder and Project Manager**

[1] Scottish Government (2018), The microsegmentation of the autism spectrum: research project, <https://www.gov.scot/publications/microsegmentation-autism-spectrum/pages/9/>

[2] Scottish Government (2019), Scottish Pupil Census 2018, <https://www2.gov.scot/Topics/Statistics/Browse/School-Education/dspupcensus/dspupcensus18> – Tables 6.11, 7.6 and 8.7

FIGURE 1: TAILOR ED'S MISSION AND VISION

Mission	Vision
Tailor Ed Foundation is a charity supporting families in Edinburgh raising a child with autism with the day to day challenges of family life.	Tailor Ed Foundation wishes to see children with autism and their families empowered and included, able to live the lives they want to and access all the day to day experiences that other families take for granted.

Much of the research available at the time indicated that a minimum of 20 hours support per week was needed to make substantive change on the types of issues that Tailor Ed hoped to help families to address, however the service's model was designed to involve far less time input by involving parents in developing strategies and providing support to the child themselves.

Initial funding for Tailor Ed came from the Big Lottery Fund through a three-year Investing in Communities grant. Since then, the organisation has gone on to access funding through a wide range of sources.

Tailor Ed's approach is based on Applied Behavioural Analysis (ABA), a behavioural approach to teaching children new skills. It is a very structured approach and there are a number of aspects to this including:

- understanding the person receiving support and what motivates them;
- understanding what tasks might lead to achieving the goals of the family and child;
- breaking down each and every aspect of the task which is being addressed into smaller steps; and
- working with the child and family to implement each of the steps required to develop a new skill.

The publication of a Scottish Intercollegiate Guidelines Network (SIGN) Clinical Guideline[3] highlighted the role of ABA in interventions for people with autism, the evidence supporting its application and the debate over low and high intensity forms of ABA intervention. It makes a recommendation that "access to support from staff trained in applied behaviour analysis-based technologies (e.g. Picture Exchange Communication System, discrete trial training, task analysis, prompting, fading or shaping) to build independence in adaptive, communication and social skills should be considered for children with ASD".

[3] SIGN Clinical Guideline 145 (2016), Assessment, diagnosis and interventions for autism spectrum disorders – A national clinical guideline; <https://www.sign.ac.uk/assets/sign145.pdf>

Tailor Ed provides support free to clients (unlike private sector alternatives). This was a fundamental tenet of the original model and remains so today. It also offers a 'whole-family' approach compared with other services which tend to focus on the child or a particular aspect of development e.g. health, education, speech etc.

In the early years of the service, the model offered home-based support to children up to the age of 12 years; ran parent support groups, workshops for parents, and information and resource evenings; and provided consultancy support to other charities (in the form of staff training). Initially, the model involved supporting parents with one issue, after which they returned to a waiting list for help with other issues.

As the service evolved, the model was revised to address demand, avoid a long waiting list, and to ensure that Tailor Ed had the biggest impact it could with the limited resources available. In 2012, the model was adjusted to include a detailed assessment process at the outset, followed by support across a range of issues.

In 2018, the model evolved further to its current form which involves two main strands – one is a Target Specific Service offered to families that have already accessed support from Tailor Ed and is available to young people up to the age of 16 years. The other strand is the Early Years' Service which provides 12 months of support to families with a child with a diagnosis of autism.

Until recently, support has been limited to families living in Edinburgh but, after a successful pilot, the Early Years' Service has now expanded into East Lothian.

Referrals to the Early Years' Service can be accepted for children entering their pre-school year. Tailor Ed has the capacity to support 35 families annually through the Early Years' Service, and this enables the service to offer a service focused on early intervention to help families address key issues and develop essential skills for life and learning in the child's early years, thereby enabling the child to be as prepared as possible for school. This time-limited service also helps Tailor Ed to meet the demand for its service, and support more families with the resources it has available at present.



Tailor Ed delivering support during the COVID-19 lockdown

Tailor Ed also offers social and fun events for children and parents including autism-friendly soft play and cinema sessions, as well as workshops for parents designed to provide group-based support on specific issues such as expanding a limited diet and getting a haircut.

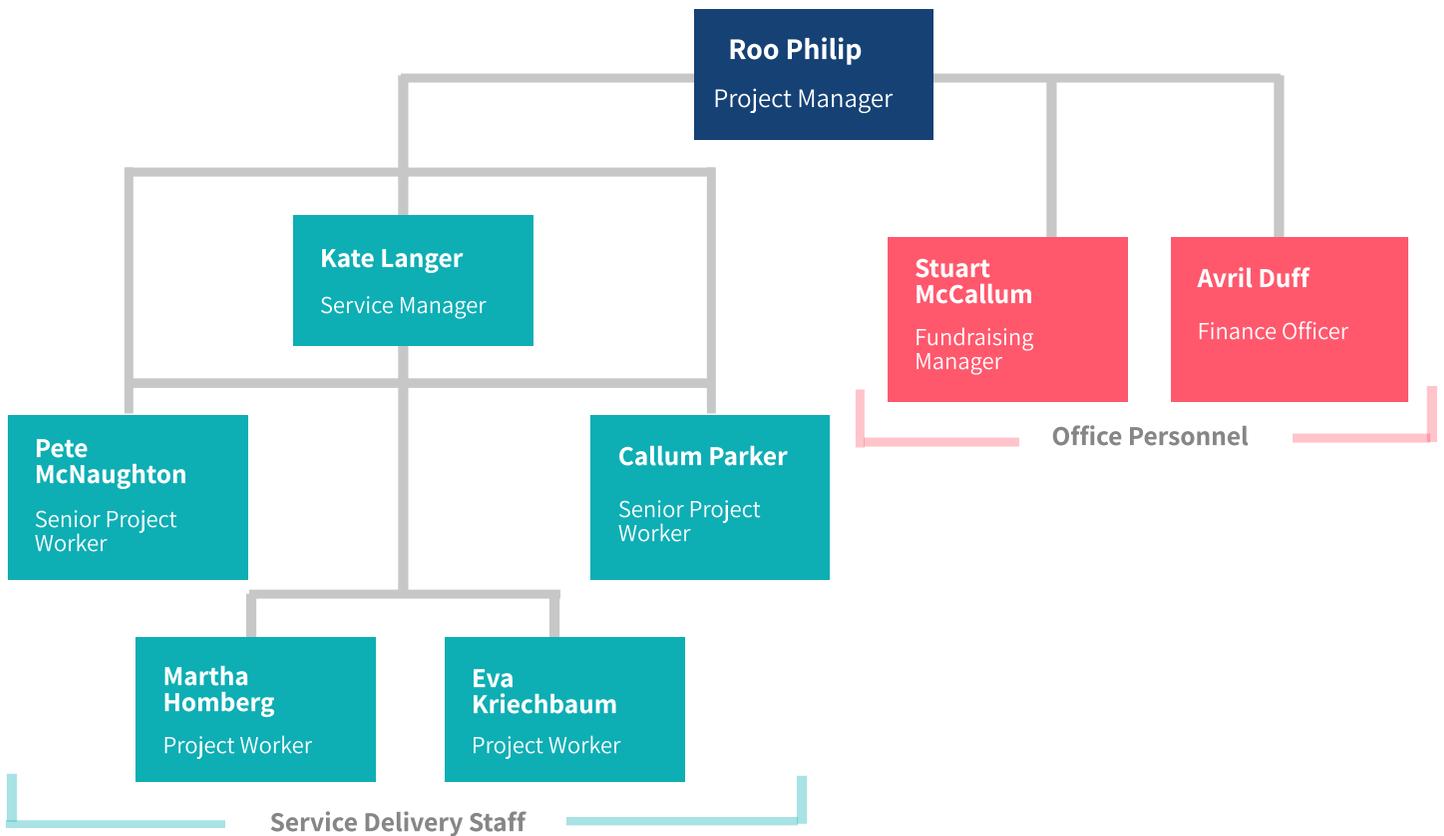
The aim has always been to offer a service which is free and accessible to all – and Tailor Ed's inclusive and non-judgemental approach means the organisation works with families who may not engage with any other services.

Staff and Board members highlighted the flexibility and responsiveness of the service compared with larger statutory services and see this as one of its key strengths – "All of our support services have evolved in response to need. Having the freedom to do that has been so important – compared to a big public sector behemoth we can be very flexible".

The service today

Tailor Ed has a team of eight as illustrated in Figure 2 below.

FIGURE 2: TAILOR ED'S ORGANISATIONAL STRUCTURE



The team is made up of dedicated individuals and their unique skill sets are considered to be key to the successful delivery of the service. Staff turnover is low (only three Project Workers have left in the last ten years), and staff often remain with the organisation for many years despite working in often challenging circumstances.

This is a real mark of their dedication to the service, and the loyalty of the staff is underlined by the retention of experienced members of staff while the organisation was having serious difficulties with funding in 2018. This low staff turnover is something that parents identify as a strength of the organisation. However, staff recruitment and retention remain ongoing challenges facing the organisation – and the nurturing environment that the organisation offers staff does not necessarily mitigate this risk.

Members of the Tailor Ed team



Governance

Tailor Ed is governed by a Board of Trustees which provides strategic direction to the organisation and support to the Project Manager. The Board meets on a monthly basis. The Board of Trustees comprises six volunteers who have been involved from the outset and one member who joined in 2015. Board members include a Consultant Psychiatrist (and Director of The University of Edinburgh's Patrick Wild Centre for Autism Research), a CAMHS Clinical Psychologist, a Children and Families Social Worker, an Additional Support Needs Primary School Teacher and the parent of a young man with autism. The Chair is a manager at the national service Autism Initiatives and the Treasurer is a Chartered Management Accountant with experience in the third sector. Board members provide expert input and guidance, and demonstrate a high level of commitment to the organisation.

Funding sources

For eight years, from Tailor Ed's establishment in 2010, the service was fully funded by the Big Lottery Fund's Investing in Communities programme. In 2018, the Big Lottery Fund reduced the funding available to Tailor Ed, which meant the service had to diversify its funding base. This was a challenging period for the organisation, but the service stayed true to its principles and sought funding that would support its service model, rather than adapting its service model in order to obtain funding.

The organisation is now in receipt of grants from several funders including:

- the National Lottery Community Fund (formerly known as the Big Lottery Fund);
- BBC Children in Need;
- the Robertson Trust;
- the Scottish Children's Lottery; and
- the Shared Care Scotland programme, Better Breaks.

The service's grant funding is supplemented by a small amount of income from revenue generating activities including delivering training for other professionals such as Pupil Support Assistants, nursery staff and other voluntary sector agencies, as well as fundraising events and corporate and personal donations.



One family supported by Tailor Ed

Tailor Ed is now exploring further opportunities for funding and income generation. The service is aiming to further diversify its income streams in order to reduce its reliance on grant funding and enhance its sustainability. In particular, the service aims to secure funding from local authorities, government and NHS, as well as increased revenue from activities like training. We discuss some potential opportunities for new funding and revenue streams in the challenges and opportunities section of this report.

Number and profile of participants

Figure 3 illustrates some key facts about the support delivered by Tailor Ed in 2019–20.

FIGURE 3: KEY FACTS (1 September 2019-31 August 2020)



Figure 4 illustrates the increase in the number of families supported annually between the service's first year (2010), and 2019.

FIGURE 4: NUMBER OF FAMILIES SUPPORTED IN 2010 AND 2019-20



Impact

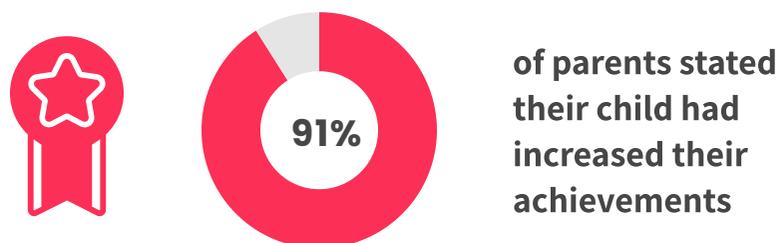
Tailor Ed's support focuses on helping children with autism to develop their skills and abilities for daily living, and to enhance parents' confidence and ability to support their children. The service has been very successful in this respect over the ten years since it was established, with overwhelmingly positive feedback from parents about their experience and the impact it has had on them and their family. Staff and Board members are also very positive about the impact of the service on families: "The impact of our service is astonishing given how straightforward some of our methods are". Staff and Board members commented on the significant differences they had observed in families, who "have often gone through many other services first", as a result of Tailor Ed's support. Previous independent external evaluations undertaken by Blake Stevenson have verified this success.

In this section, we summarise the impact that Tailor Ed has had on the children and families it has supported so far, based on feedback collected by the service over the past ten years and a series of case studies that we recently conducted with six families.

Impact on children

Tailor Ed has a very strong track record in helping children with autism to make significant improvements in a wide range of skills for daily living. The service delivers tailored support to help families with the issues of most importance to them, including a very wide variety of skills and issues. For example, Tailor Ed has supported children to develop skills including communication, dressing, sleeping, eating new foods, climbing the stairs, toileting, washing, riding a bike and following a morning routine, and there are several cases where the service has helped children to feel more comfortable and willing to do things like going to the dentist, getting their hair cut and using public transport.

FIGURE 5: IMPACT ON SERVICE USERS (AS REPORTED TO TAILOR ED IN 2018-19)



While developing these skills is a valuable outcome in itself, it also has a positive knock-on effect on the child's life more generally.

In some cases, this includes enhanced safety. In 2018-19, 82% of parents said their child is safer as a result of Tailor Ed's support.

For example, Tailor Ed supported a child to learn how to climb stairs independently, and this helped to reduce the risk of her falling and made it easier for her family to leave their flat safely. In another example, Tailor Ed helped a family to manage their son's aggressive behaviour which had made his mother concerned for his safety and that of the rest of the family.

In other cases, the new or improved skills have helped children to integrate and take part more fully in the community. In 2017, 87% of parents said their child is more involved in daily life as a result of Tailor Ed's input, and in 2018-19, 90% said their child was more included. For example:



The support provided to one non-verbal child enabled him to communicate with his family and other people. This was crucial in helping to prepare the child for starting school, with the assistance around communication and fine motor skills particularly valuable.



In another case, Tailor Ed helped a family to manage their child's challenging behaviour when he was 8 years old and again when he started secondary school. This helped him to integrate more successfully into secondary school and to interact better with his peers and teachers.



Tailor Ed's support with communication and following instructions meant that one girl was "much readier for starting school than she would have been".

“There was a great risk of exclusion from school if not for Tailor Ed”.



One parent reflected that her daughter would probably be in residential care by now were it not for Tailor Ed, but is still living at home with her family and attending a specialist school for children with autism.

We provide more information about one child's experience and the support Tailor Ed provided to help them prepare for school below (we have changed the child's and mother's names in this case study to protect their anonymity).

FREDDIE'S STORY

Tailor Ed supported Freddie, who is now 8 years old, as part of the pilot phase of its Early Years' Service. A friend recommended Tailor Ed to Freddie's mum, Gemma, in 2014, when he was 4 years old.

At the time, Freddie had just been diagnosed with autism, and, although Freddie received support at nursery, Gemma said they were **"not getting an awful lot of support at home"**. Gemma was keen for help with communication and fine motor skills in particular.



Tailor Ed visited the family every week for one year and helped with a few different issues before Freddie started school. This included introducing the PECS communication system to the family, helping with haircuts and toilet training as well as devising 'shoebox tasks' to help him with his fine motor skills.

Overall, Gemma described the support as **"a lifeline"** and said that things **"would have been a lot more difficult"** for Freddie and the rest of the family without Tailor Ed.

✓ The support with communication was **"the starting point of his communicating with us - a big thing for us"**. Gemma said that Freddie displayed less frustration as a result, and using PECS has helped his younger brother to interact and play with him.

✓ Freddie is also now **"very good at getting his hair cut without any bother"** and the results of the support with toilet training were **"fantastic"**.



The support helped to prepare Freddie for starting school. PECS has helped him to communicate more effectively with teachers and other pupils, and the shoebox tasks helped him to get used to following instructions and doing activities using fine motor skills.

✓ Gemma and her husband learned important skills from Tailor Ed that have made them more confident and equipped to support Freddie. For example, the family has continued to use PECS to support Freddie's communication.

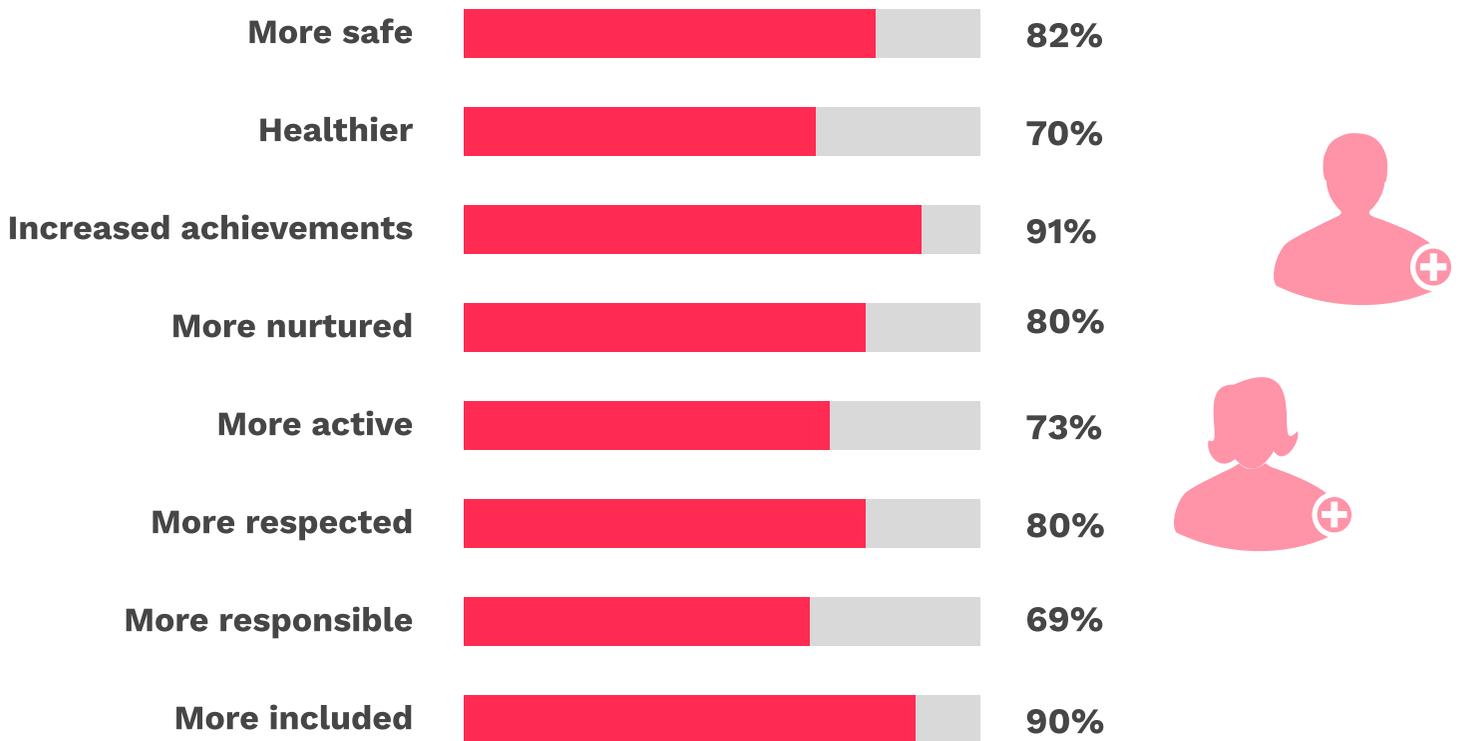
✓ Gemma also noted social benefits of Tailor Ed's support. She made some friends at autism-friendly soft play sessions provided by Tailor Ed and has kept in touch with one or two parents she met at a night out organised by Tailor Ed.

✓ Gemma praised the service's child-focused approach. She values the way that Tailor Ed talk directly to the child, unlike other services, as this helps them to get to know the child and to tailor their approach to the child's needs and interests.

Children also display improved confidence as a result of gaining new and improved skills. For example, one parent said her son’s “confidence in who he was and in being himself grew enormously” and another reported that “he believed in himself because they did”.

In 2018–19, Tailor Ed collected data related to their contribution to the SHANARRI indicators, and this provides further evidence of the service’s positive impact on children and families (Figure 6).

FIGURE 6: HOW FAMILIES DESCRIBED THE IMPACT THE SERVICE HAS HAD ON THEIR CHILD



Impact on parents

Tailor Ed’s support has a highly positive impact on parents it supports in a number of ways. Through Tailor Ed’s assistance, parents learn new skills and as a result become more confident and feel better equipped to support their child (Figure 7).

FIGURE 7: IMPACT ON PARENTS' SKILLS AND CONFIDENCE (AS REPORTED TO TAILOR ED IN 2017-18)



By teaching parents these new skills, Tailor Ed empowers them to use the techniques they learn and apply them independently to the same issue and others. One parent said, "Because of the skills they gave us, we were able to implement our own plans". Another said the support "set us up for a lifetime of parenting".

"[Tailor Ed's support] was a transformational point in my parenting journey. I stopped seeing myself as a useless parent".

Another parent noted that he was able to make more progress with his son's diet after Tailor Ed's initial support, to the extent that his son now cooks his own dinner every evening. In a third case, Tailor Ed helped a child to become more comfortable having his hair cut and he was willing to have a mobile hairdresser come to his house. Following Tailor Ed's input, his parents used the techniques and principles that the service had introduced in order to make further progress, and he was soon willing to have his hair cut in a barber shop.

Parents also reported that, by learning new skills and techniques to support their child, and as a result of Tailor Ed's positive, can-do attitude, they feel more positive about having a child with autism. They realise that the challenges they experience are not insurmountable, and begin to see what their child is capable of. For example:



One parent said he appreciated being able to "get stuff off my chest" through chatting with staff, and that he "got acceptance from them, that there's nothing different about having an autistic child".



Another parent said that "you feel quite isolated, so just having a nice, person educated about autism come to your house to talk to, straightaway that made a positive impact on me".



In a powerful example, a parent described how she had experienced depression following her child's diagnosis with autism, but Tailor Ed's support "taught you to be positive about having a child with autism" and showed the family practical techniques they could use to address the challenges they were facing, and this helped to improve her mental health. We provide more details about this example in the case study below (we have changed the child's and mother's names in this case study to protect their anonymity).

PETER'S STORY

Peter is 14 years old and lives with his Mum (Ellen) Dad and younger sibling. He was diagnosed with autism when he was 3 years old. Another support provider initially supported the family after the diagnosis but Ellen did not find that support particularly helpful so, when her mum's friend told her about Tailor Ed, she got in touch and asked for help.



Tailor Ed helped Peter with toilet training when he was 4, tapping into his interest in Power Rangers to engage him and encourage him to use the toilet.

- ✓ Ellen felt Tailor Ed's approach helped to make it clear to him what he was being asked to do.
- ✓ The support with toilet training helped him to consistently use the toilet in different environments.

“it was like a light going off in Peter's head - 'that's what you want me to do!'”



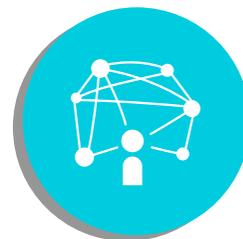
When he was 6 years old, Tailor Ed helped Peter to get his hair cut.

- ✓ The input on haircuts made him feel more comfortable having his hair cut.

At 12 years old, the service helped him to develop and follow a visual timetable to get out of bed, wash, dress, eat breakfast and ready to go to school independently.



Ellen said the support “really helped for his development” and has “given him a life”. She commented that Peter “believes in himself because they did”.



- ✓ Ellen also reported that she and her husband learned a lot from Tailor Ed about autism and this helped to enhance their confidence and skills in supporting Peter: **“Because of the skills they gave us, we were able to implement our own plans”.**
- ✓ Tailor Ed's support also had a positive impact on Ellen's mental wellbeing. She said that she was depressed when Peter was first diagnosed with autism. Tailor Ed **“taught you to be positive about having a child with autism”** and showed the family practical techniques they could use to address the challenges they were facing, and this helped to improve her mental health.
- ✓ Ellen has recently gone back to work, and this would not have been possible without the increased independence in the mornings that Peter has achieved as a result of Tailor Ed's support

As well as building skills and confidence in parenting, parents described the social benefits of Tailor Ed's support. The service offers social events for families as well as for parents to attend without their children. These events allow parents to meet other parents in a similar situation, and this offers a valuable source of shared experiences, advice and moral support.

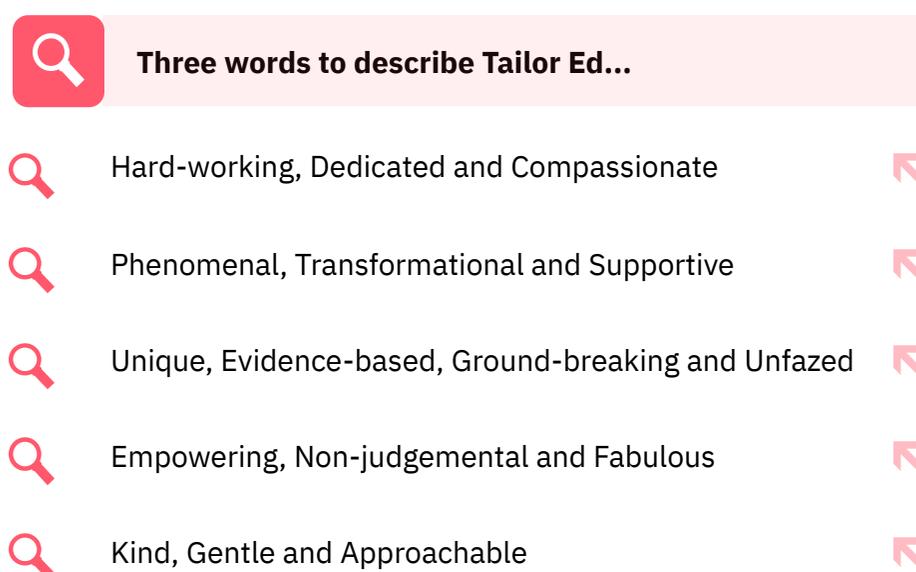
Impact on the wider family

By helping children to develop important skills for daily living, and by helping parents to feel more confident and equipped to support their child, Tailor Ed's support has benefits for the wider family. The changes in the child's behaviour can make home life less stressful for the entire family, and this can help to improve relationships among family members. For example, one child developed his communication skills and this helped him to interact and play with his younger sibling. It also helped him to express his needs, which made him less frustrated and made family life more harmonious. In another example, Tailor Ed's support with diet and routines helped to improve a boy's relationship with his parents significantly.

By enhancing the child's independence and ability to do things for themselves, this can reduce stress and potential flashpoints, and gives other family members more time and independence too. For example, one mum has recently gone back to work, and the increased independence in the mornings that her son has achieved as a result of Tailor Ed's support has helped with this.

Overall, parents are extremely satisfied with Tailor Ed's support and described many benefits for the child, themselves as parents and the wider family. The consensus is that Tailor Ed offers a highly personalised and extremely effective service that provides a "lifeline" to families when they need it most. We asked parents to identify three words they would use to describe Tailor Ed. Their responses are a really positive endorsement of the service provided.

FIGURE 8: HOW PARENTS DESCRIBED TAILOR ED



Cost benefits of the service

Tailor Ed is a small charity, operating on a budget of around £275,000 annually. The extent of impact being delivered for this level of budget is significant. While no formal cost benefit study has been conducted to date, internal assessments of cost benefit indicate significant longer-term savings being achieved through the service. These include the following:

- Less family expenditure on items such as clothes and/or bedding if the child has toileting problems beyond the expected age.
- Reduction in a family's transport expenditure if their child is more able to cope with public transport and the family do not have to rely on taxis.
- Reduction in parental time off work.
- Reduction in the number of children in special needs schools due to improvements in communication skills and/or challenging behaviour making it easier for some children to engage with mainstream education.
- Reduced costs to the health service of, for example, general anaesthetics for routine dental treatment.
- Improved mental health meaning that the young people are less at risk of needing support from services such as Child and Adolescence Mental Health Service (CAMHS).
- Improved mental wellbeing of parents, reducing their need for mental health services.

Key success factors

In Figure 9, we illustrate some of the key factors that have contributed to Tailor Ed's success, based on feedback from parents, children, staff and Board members.

One Tailor Ed beneficiary

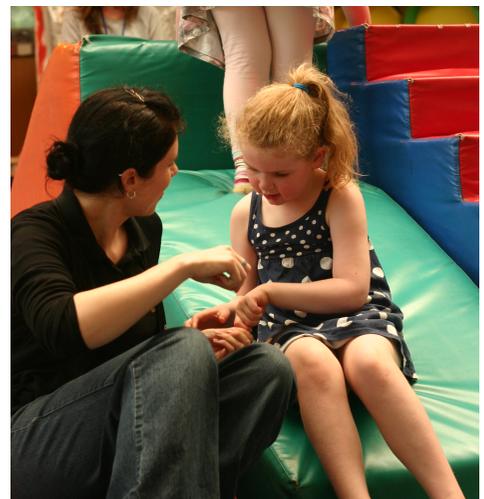
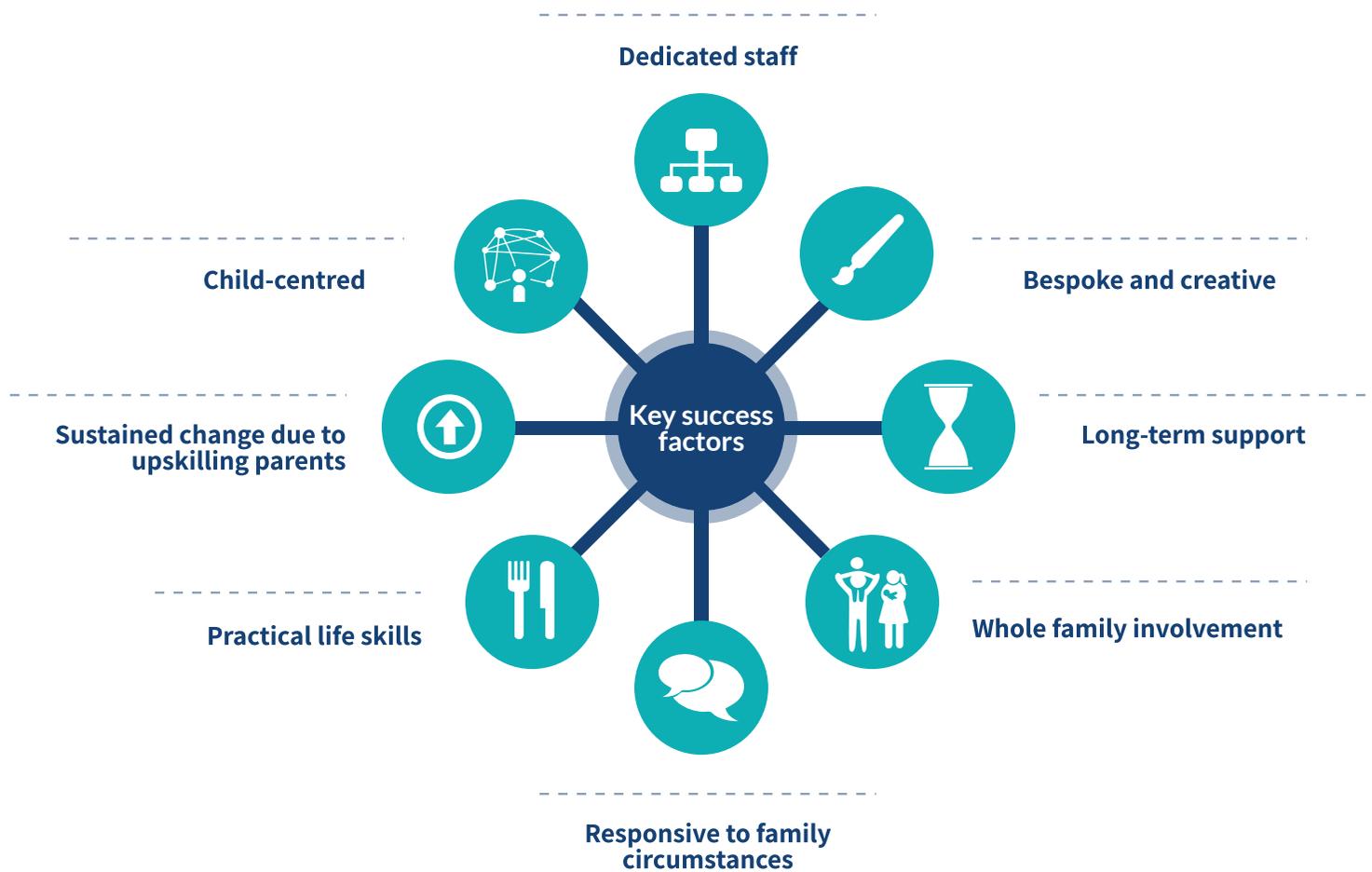


FIGURE 9: KEY SUCCESS FACTORS



We provide some more details about each of these factors below.

Dedicated staff

Many interviewees commented on the dedication of the staff. A staff member identified the focus and dedication of the service as a key strength: “We know what we’re good at – we have a strong specialism and we are passionate about it”. A parent said “they have a deep working knowledge of the kids and the families”.

Bespoke and creative

Parents are impressed by the work Tailor Ed do to get to know their child, and the creativity shown in developing tools and materials tailored to their child’s interests.

“You wouldn’t get this sort of intervention from statutory services”.

Long-term support

Parents spoke positively about the length of time that Tailor Ed spends with each family.

“Other services would only give six weeks or so. Tailor Ed said our service will stop when this is working – this differentiates it from other services”.

“A target is set and Tailor Ed hang around until it’s met. What happens with statutory services we have worked with is you get given three or four sessions or it’s very time limited and then that’s that”.

Parents reported often staying in touch with the service through its various forms of support on and off over a number of years to address new challenges as they emerge. An example of this is one parent who told us she appreciates being able to talk on the phone with Tailor Ed every few months about her son and any challenges they are facing, because the workers know him intimately having worked with him from a young age. In another case, Tailor Ed first worked with a child at age 4 to help with toilet training, at 6 to help him feel more comfortable with getting his hair cut, and again at 12 to help with developing a morning routine that he could follow independently.

Tailor Ed has now introduced its Early Years’ Service, with a limit of one year of intensive one-to-one support. This means there has been a shift away from the service providing multiple pieces of home-based one-to-one support over a number of years, in order to ensure that it can take on more families each year while avoiding a lengthy wait list. This was a necessary step to help Tailor Ed manage the demand for the service within the capacity it has available, and the service has found that providing this support at an early stage enables it to meet the needs of families with fewer (and sometimes no) home visits to work on additional targets beyond the initial 12 months’ support. However, it is important to note that families can still access the Target Specific Service up until the child turns 16. In addition, other Tailor Ed support services, including workshops and family events, remain open to families beyond the initial 12 month period.

Whole family involvement

The service involves the full family in its support, recognising that family dynamics have an impact on the child’s behaviour and skills, and vice versa. A staff member noted that “going into families’ homes gives us unique insight and makes a huge difference to the relationship with the families we support”. There are several examples of Tailor Ed’s support involving the whole family. For instance, in one case, Tailor Ed made a chart for the child’s younger sister to keep her involved.

Responsive to family circumstances

Tailor Ed produces individualised action plans and approaches tailored to each individual family's needs and circumstances. A staff member observed that "we tailor our strategies to families' every day realities. We put in place fair and reasonable support measures that don't place additional stress on the families". A parent noted that "there is no off the shelf assumption with Tailor Ed – everything is individualised" and another praised the service for taking "time to get to know a child and family dynamics".

Practical life skills

Tailor Ed's support focuses on helping children with autism to develop skills for daily living that will help them later in life. There are several cases where the service helped children with autism to develop the skills they need to start school, for example. One parent contrasted Tailor Ed's approach of focusing on practical life skills favourably with that of other services which aimed to teach her child about colours and shapes.

Sustained change due to upskilling of parents

Tailor Ed aims to empower the families it works with by teaching them strategies and techniques that they can apply independently to support their child after Tailor Ed has withdrawn.

This helps to ensure that the progress made during Tailor Ed's support is sustained in the long-term by the parents without help from Tailor Ed. A staff member said that "our support empowers parents to deal with other issues" and parents gave several examples of learning useful skills from Tailor Ed that helped to improve their confidence and ability in supporting their child.

Child-centred

Parents noted that, unlike other services they have been involved with, Tailor Ed speaks directly to the child instead of focusing solely on the parent. Parents observed that this helps the worker to get to know the child and tailor their approach to the child's needs and interests.

Parents also commented on Tailor Ed's skills in working and building rapport with children with autism, and they value the fact that Tailor Ed, unlike some other services, recognises that all children are different with various motivators and abilities, and that what works for one child will not necessarily work for another.

“That’s the value of Tailor Ed – it’s working towards being included in the community and learning to learn skills that are valuable for the rest of our lives and for [our child]”.

Challenges and Opportunities

As it celebrates its tenth birthday, Tailor Ed is facing a number of key challenges and opportunities, and we summarise these below.

Funding and income generation

Tailor Ed operates within a challenging and competitive funding environment, and, in particular, over the years, accessing funding from statutory services has been a key challenge for the service. No funding has been made available to date from NHS Lothian, despite the positive outcomes that Tailor Ed has achieved for families.

However, the service has recently been successful for the first time in accessing funding from local authorities, with grants from both City of Edinburgh and East Lothian Councils. This is a significant achievement and recognises the positive impact that the service has had on families.

The service aims to reduce its reliance on grant funding and identify further opportunities for revenue-generating activities, while retaining its ethos of not charging families for the support it provides. This is a pragmatic approach and will help to enhance the organisation's sustainability, and staff and Board members identified some activities that could potentially generate income for Tailor Ed. For example, staff suggested that Tailor Ed could offer training in ABA for other organisations and another staff member suggested that, with the roll out of increased Scottish Government-funded childcare provision for the early years, the service could train nursery staff to help them better support children with autism.

While there are opportunities for further grant funding and revenue-generating activity, staff emphasised the importance of retaining the service's focus on quality as it develops further, and of continuing to look for funding that fits the needs of the service, rather than changing the service to meet the needs of funders.

Geographical expansion

Tailor Ed has an excellent reputation and track record of success in Edinburgh, and has recently extended its Early Years' Service into East Lothian following a successful pilot. It is also looking to expand into West and Midlothian.

Existing coverage ■
Proposed areas for expansion ■



Staffing

As noted above, Tailor Ed's skilled, experienced and dedicated staff team is a key strength of the service. While Tailor Ed's level of staff retention is exceptionally good, staff noted a challenge in recruiting new staff because people qualified in ABA are hard to find and training in this approach takes significant investment. This further emphasises the importance of maintaining the service's already high levels of staff retention.

Tailor Ed also has an aspiration to obtain funding for and recruit a new Support Worker role in the future. This person would support the Project Workers by focusing on providing informal advice and signposting for parents (eg on primary-secondary school transition) and on "forging a community" by organising social events. Project Workers currently undertake these tasks but having a Support Worker would help to free up Project Workers' time for more specialised target-based behavioural work with children and families.

COVID-19 pandemic

Tailor Ed's service users were confronted with several challenges when the public was advised to stay indoors as a result of the COVID-19 pandemic. While families welcomed the opportunity to spend more time together, there were also difficulties as children and families struggled with the sudden change to their circumstances and routines. Schools, nurseries and activities like swimming were suddenly closed and informal sources of respite childcare, such as grandparents, became unavailable to families. As a result, families reported increases in issues like challenging behaviour, stress, anxiety and feelings of isolation as a result of the lockdown.

This led to a huge increase in the need for support among families working with Tailor Ed. In the first four months after the crisis began in March 2020, the Target Specific Service delivered 815 appointments which was more than the 807 appointments it had delivered in the previous 12 months.

The lockdown also necessitated a change in service delivery methods, with Tailor Ed achieving a rapid shift from a face-to-face approach to the remote delivery of support using digital platforms. In March 2020, all face-to-face work was suspended and one-to-one support for children with autism and parents was transferred onto digital platforms. To illustrate the extent of this change, of the 983 support appointments delivered in family homes between September 2019 and August 2020, only eight took place after lockdown. Video call appointments increased from zero between September 2019 and February 2020 to 1,043 in the period from March to August 2020. Similarly, phone-based support increased from 67 appointments to 542, and email/text from zero to 107.

The service also offered a programme of online-based group activities. These included Circle Time, an activity and story-telling session delivered on Zoom to help compensate for the lack of routine caused by the closure of schools and nurseries. 'Tiger School' – online sessions focused on reading, writing and numeracy – was also introduced.

The service found that, while some children found it difficult to engage with digital support, their parents appreciated the convenience and continuity of support that this has offered. There were also some challenges with a few families who lacked access to IT resources, but the service was able to help families in some cases to access the necessary equipment to engage with Tailor Ed online.

The service found that some families did not have access to other resources they needed to cope with the lockdown. In total, the service helped to make 120 purchases of IT or play equipment such as paddling pools and tents for families to support them spending increased time at home. In addition, the service delivered 177 bespoke packs of activities and visual support materials for families who needed them.

Tailor Ed also delivered support to parents of children about to begin primary school to help prepare for the transition to school, including help to develop coping strategies. Families taking part in the Early Years' Service received an extra four months of support between September and December to help with this. This was important because the children were not able to receive preparatory support that would normally have been delivered by nurseries while those settings were closed during lockdown.

Families provided very positive feedback about Tailor Ed's support during lockdown. Two-thirds of 28 parents who responded to a Tailor Ed survey said that they had received more support from the service during lockdown than before and 92% reported this had helped "a lot". Parents reported that the support helped to compensate for the isolation and loss of routine caused by the lockdown. Some comments from parents are below.

"My son's favourite activity was undoubtedly Circle Time and it was a joy to watch him take ownership of this himself, appearing promptly in the kitchen with his ipad at 9.58 each morning ready to log himself in, without me calling him".

"Tailor Ed checked in with me frequently over lockdown... [they] dropped off resources for now and next, visuals, sent out games".

"The project worker helped my son manage his anxieties and developed strategies to help him keep calm".

"It has been fab to see the one-to-one work with my child at Tiger School. He has loved it. It been a great routine and he has learned to read, write and spell. It was mostly the only school work he would do".

Some parents also described the positive difference that Tailor Ed made for their mental wellbeing during lockdown. Parents faced challenges in having their children at home all day every day, and often they were juggling work commitments too. Parents explained that Tailor Ed helped them develop coping strategies as well as providing a routine and activities for their child.



Zoom session with a young person with autism

The future

Tailor Ed's focus remains targeted intervention support and the service is currently investing in and growing its staff team to deliver this type of support. The service is also keen to build on the success of its Early Years' Service which has achieved positive results for families. The first cohort of 35 children in the Early Years' Service came to an end of their intensive support in December 2020, and a new cohort of 35 children with autism and their families began working with their dedicated support worker in January 2021. Tailor Ed is keen to remain true to its core purpose, and it believes that there continues to be a significant demand for the service.



Tailor Ed Zoom team meeting

Tailor Ed has responded quickly and ably to the challenges posed by COVID-19, maintaining support with daily living skills and helping families to address the new challenges caused by the pandemic. The diversification of delivery methods has provided the service with valuable learning points. The service's default approach remains to offer support remotely via digital platforms as the pandemic continues. If necessary for a child's wellbeing, it also continues to offer face-to-face work following a careful risk assessment, and where restrictions allow. The service plans to maintain some of the innovations introduced in response to the pandemic in the future. For example, online Circle Time sessions will be offered to help maintain routines during 'normal' school holidays.

Another key focus for the service has been broadening its geographical reach beyond Edinburgh and it has recently expanded its Early Years' Service into East Lothian following a successful pilot. This is a positive development and the potential for further expansion into other parts of the Lothians is also being explored as the service continues to develop.

Appendix 1: Case Studies

Below we present a series of case studies that illustrate the impact that Tailor Ed has had on families it has supported over the past ten years. We have changed the names of the children and parents in these case studies to protect their anonymity. For each case study, there are two versions – a short summary and a more detailed version. The summaries of the Freddie and Peter case studies are presented in the main body of the report, while the others are included in this appendix.

Freddie

Tailor Ed supported Freddie, who is now 8 years old, as part of the pilot phase of its Early Years' Service. A friend recommended Tailor Ed to Freddie's mum, Gemma, in 2014, when he was 4 years old. At the time, Freddie had just been diagnosed with autism, and, although Freddie received support at nursery, Gemma said they were "not getting an awful lot of support at home". Gemma was keen for help with communication and fine motor skills in particular.

What issues did Tailor Ed help with?

Tailor Ed visited the family every week for one year and helped with a few different issues before Freddie started school. As Freddie was non-verbal, he had no way of communicating with his family and Gemma said this was "probably the hardest part". Tailor Ed introduced the PECS communication system to the family and supported them to start using it.

Tailor Ed also helped Freddie with haircuts and toilet training as well as devising 'shoebox tasks' to help him with his fine motor skills.

What impact has Tailor Ed's support had on Freddie and his family?

Tailor Ed's support with Freddie's communication was very important for the family. Gemma described this as "the starting point of his communicating with us – a big thing for us" as it meant that Freddie became able to communicate his thoughts, feelings and preferences with his family. Gemma said that Freddie displayed less frustration as a result, and using PECS has helped his younger brother to interact and play with him.

Gemma also reported that he is now "very good at getting his hair cut without any bother" and the results of the support with toilet training were "fantastic". He still has to wear pads but is able to go to the toilet.

The cumulative effect of Tailor Ed's support was to help prepare Freddie for starting school. Gemma credits the work on PECS with enabling him to communicate more effectively with teachers and other pupils than he would have been able to without Tailor Ed's support, and the shoebox tasks helped him to get used to following instructions and doing activities using fine motor skills in the way he would be expected to at school.

Crucially, Gemma and her husband learned important skills from Tailor Ed that have made them more confident and equipped to support Freddie. For example, the family has continued to use PECS to support Freddie's communication. Similarly, Tailor Ed started Freddie's toilet training process then the family were able to continue working on the issue independently, using the skills they had gained from Tailor Ed.

Gemma also noted social benefits of Tailor Ed's support. She made some friends at autism-friendly soft play sessions provided by Tailor Ed and has kept in touch with one or two parents she met at a night out organised by Tailor Ed.

Gemma identified another benefit of the soft play sessions, commenting that it was "nice to be able to go somewhere where you don't feel guilty if your child does something and you can't explain it". Overall, Gemma described the support as "a lifeline" and said that things "would have been a lot more difficult" for Freddie and the rest of the family without Tailor Ed.

Views of Tailor Ed's approach and ethos

Gemma praised the service's child-focused approach. She values the way that Tailor Ed talk directly to the child, unlike other services, as this helps them to get to know the child and to tailor their approach to the child's needs and interests.

She also valued the dedicated and comprehensive support that the service offers, describing an example of Tailor Ed staff working with Freddie all day and "watching like a hawk" for signs that he needed the toilet in order to support his toilet training.

Steven

Steven is 15 years old and lives with his mum (Yvonne), dad and younger siblings. He was diagnosed with autism and motor planning difficulties when he was 4 years old. Yvonne first heard about Tailor Ed through the NHS when Steven was first diagnosed, and self-referred to Tailor Ed at that point. After some time on the waiting list, the family started receiving support when Steven was 7.

What issues did Tailor Ed help with?

Steven found it difficult to follow instructions and frequently displayed challenging behaviours in response to being told what to do, including shouting, pushing, scratching, hitting and kicking. This was becoming more of an issue as he became bigger, and was disruptive and distressing for the family, as well as dangerous. Yvonne said “it was frightening... I wasn’t seeking help for him to brush his teeth, I was trying to stop him hurting himself and others”.

The focus of Tailor Ed’s support when Steven was 7, in an 18-month long period of intensive home-based support, was to enable Steven to follow instructions from adults without displaying challenging behaviours. Using roleplay scenarios with toy characters, as well as a token system to reward positive behaviour and disincentivise challenging behaviours, Tailor Ed gradually taught Steven how to follow instructions.

In 2017, when Steven was 13, Tailor Ed provided further support on this issue when Steven’s challenging behaviour began to re-appear when he moved to high school. The school seemed to be close to excluding him, but Tailor Ed helped Yvonne by attending meetings with the school and suggesting steps the school could take to better integrate Steven. The service also supported Yvonne to devise a way for Steven to indicate he was feeling overwhelmed and about to have a meltdown by using the phrase ‘I need space’. This gave him a method to remove himself from a stressful situation before it escalated. The family has also taken part in several Tailor Ed social events and workshops over the years, including one where Steven learnt how to ride a bike. Yvonne is in regular contact with the service, and has telephone consultations every three to six months to discuss Steven’s progress and challenges.

What impact has Tailor Ed’s support had on Steven and his family?

Tailor Ed’s input led to improvements in Steven’s ability to follow instructions from adults without displaying challenging behaviours. A Tailor Ed worker said that “initially there would be aggressive behaviour and it could take Steven up to an hour to complete the demand but after working through this a few times the behaviour decreased as did the time and he would generally follow instructions well”. Yvonne confirmed that “by showing Steven that aggressive behaviour wouldn’t get him what he wanted... he was able to learn an alternative communication strategy. We taught him to say ‘I’m angry’ instead of using his fists”.

In 2017, when Steven's challenging behaviour re-appeared at school, Tailor Ed played an important role in supporting Steven, the school and his parents to manage his behaviour. This meant he was better able to interact with his peers and teachers, and became better integrated into the school community. Yvonne said "there was a great risk of exclusion from school if not for Tailor Ed. If he had not learnt to follow instructions, he would have been denied education".

Yvonne also observed that, by being better able to manage his behaviour and to communicate verbally rather than physically, he has become less anxious. As a result, "he's more able to take an interest in other people. He's more able to ask people how they are. He's not locked into himself anymore". As well as the direct impact of Tailor Ed's support on Steven, Yvonne identified benefits for her, Steven's dad and siblings. She commented that she and her husband have learned from Tailor Ed about techniques to use to manage Steven's behaviour, and have been able to apply these independently. Yvonne also spoke of the benefits of being able to talk to someone about Steven and autism. Tailor Ed has been an on-going source of support for her since the first referral, and she values being able to talk to them on the phone every few months: "As a parent, you feel quite isolated, so just having a nice, person educated about autism come to your house to talk to, straightaway that made a positive impact on me".

If Tailor Ed's support had not been available, Yvonne thinks there could have been very serious consequences for her family: "We would have been in despair... there was a really strong chance that my family would've broken down".

Yvonne and her husband have had two more children since Tailor Ed's initial intervention and she said that, were it not for Tailor Ed, they would probably not have felt able to have any more children. Looking further forward, Yvonne also suspects that Steven might have got into trouble with the police if he had continued to display the same challenging and aggressive behaviours.

She also predicted that Tailor Ed's support in developing Steven's ability to follow instructions will help Steven when he is looking for voluntary or paid employment: "The likelihood [of Steven gaining employment] has increased since he has learnt the ability to follow instructions – it's required in every kind of work".

Views of Tailor Ed's approach and ethos

Yvonne was full of praise for Tailor Ed. Although the family had to wait on a waiting list for around two to three years until Steven was 7, she felt the waiting list process was well-handled. There was good communication from Tailor Ed and they were able to access workshops (group-based support for parents) in the interim.

Yvonne praised the Tailor Ed worker who supported Steven, noting that she "didn't lose her cool during the process and came back day after day", despite Steven becoming violent in some of the sessions. She also liked the way the worker got down on the floor to play with and get to know Steven when she first met him, and that the approaches devised by Tailor Ed were age-appropriate and tailored to Steven's needs and interests. Steven said Tailor Ed staff are "very nice to me". He sees them as friends and enjoys going to Tailor Ed social events.

This is in contrast to another service that the family has experience of, which Yvonne described as “ignorant, unsympathetic, fundamentally unsuited to working with autistic children. Their solutions were trying to fit a square peg into a round hole”.

Tailor Ed’s first intervention with Steven took quite a long time around 18 months. Yvonne noted that this was a process of iteration and appreciated the intensive and non-time-limited nature of Tailor Ed’s support, unlike some other services: “other services would only give six weeks or so. Tailor Ed said our service will stop when this is working – this differentiates it from other services”.

STEVEN'S STORY

Steven is 15 years old and lives with his Mum (Yvonne), Dad and younger siblings. He was diagnosed with autism and motor planning difficulties when he was 4 years old.

Steven found it difficult to follow instructions and frequently displayed challenging behaviours in response to being told what to do, including shouting, pushing, scratching, hitting and kicking. This was becoming more of an issue as he became bigger, and was disruptive and distressing for the family, as well as dangerous. Yvonne said **“it was frightening... I wasn't seeking help for him to brush his teeth, I was trying to stop him hurting himself and others”**.



When Steven was 7, Tailor Ed taught Steven how to follow adult instructions without challenging behaviours, using roleplay scenarios and a token system.

Yvonne reported this was successful: Yvonne confirmed that **“by showing Steven that aggressive behaviour wouldn't get him what he wanted... he was able to learn an alternative communication strategy. We taught him to say 'I'm angry' instead of using his fists”**.

In 2017, when Steven's challenging behaviour re-appeared at school, Tailor Ed played an important role in supporting Steven, the school and his parents to manage his behaviour.

As a result, Steven became better able to interact with his peers and teachers, and became better integrated into the school community.

“There was a great risk of exclusion from school if not for Tailor Ed. If he had not learnt to follow instructions, he would have been denied education”.

Now, Steven is still in school and hopes to move on to paid or voluntary employment after he leaves. Yvonne feels **“The likelihood [of Steven gaining employment] has increased since he has learnt the ability to follow instructions - it's required in every kind of work”**.

Yvonne commented that she and her husband have learned from Tailor Ed about techniques to use to manage Steven's behaviour, and have been able to apply these independently. As well as the direct impact of Tailor Ed's support on Steven, Yvonne identified benefits for her, Steven's dad and siblings. She commented that she and her husband have learned from Tailor Ed about techniques to use to manage Steven's behaviour, and have been able to apply these independently.

If Tailor Ed's support had not been available, Yvonne thinks there could have been very serious consequences for her family: **“We would have been in despair... there was a really strong chance that my family would've broken down”**. Looking further forward, Yvonne also suspects that Steven might have got into trouble with the police if he had continued to display the same challenging and aggressive behaviours.

Yvonne was full of praise for Tailor Ed. She liked the way the worker got down on the floor to play with and get to know Steven when she first met him, and that the approaches devised by Tailor Ed were age-appropriate and tailored to Steven's needs and interests. Steven said Tailor Ed staff are **“very nice to me”**. He sees them as friends and enjoys going to Tailor Ed social events.

Yvonne appreciated the intensive and non-time-limited nature of Tailor Ed's support, which is in contrast to some other services: **“other services would only give six weeks or so. Tailor Ed said our service will stop when this is working - this differentiates it from other services”**.



Lewis

Lewis was diagnosed with Asperger's Syndrome when he was six years old. He is high functioning in many ways but when he started nursery he had significant challenges and became very isolated as a result.

Lewis was overwhelmed by stimulus like television, could not cope with any changes to his routine, and had significant challenges with eating (due to problems with his co-ordination) which would result in him having to change his clothes after every meal. He would frequently lash out.

Lewis attended The Yard with his family and it is there that they found out about Tailor Ed. Tailor Ed provided him with a range of support over a one year period.

What issues did Tailor Ed help with?

The service worked with him to improve his eating skills and helped his family to establish routines, such as fixed bedtimes, with him. Tailor Ed staff used a range of methods to support the family, including introducing a rewards scheme. His mum, Laura, described how Tailor Ed "really understood him". The workers showed Laura that he did not use his left hand at all and they helped him with tasks to improve his co-ordination.

What impact has Tailor Ed's support had on Lewis and his family?

He responded very positively to the 1:1 support that he received and this resulted in a huge improvement in his skills. Laura described how this also impacted Lewis's confidence – "His confidence in who he was and in being himself grew enormously". It also led to his relationship with his family improving significantly. His family were able to apply their learning to other circumstances – Laura said "it was a transformational point in his life and my parenting journey with him. I stopped seeing myself as a useless parent".

Laura also attended parent sessions facilitated by Tailor Ed which she found highly valuable – "It suddenly didn't feel like I was on my own".

Views of Tailor Ed's approach and ethos

Laura was very positive about Tailor Ed's approach, including the way that other support was also provided to the family – for example, the workers made a chart for his younger sister to keep her involved, and they engaged with his school teacher to make sure she was aware of the approaches that worked best with Lewis.

"We are so grateful to Tailor Ed – we would recommend them to everyone in our situation".

LEWIS'S STORY

Lewis was diagnosed with Asperger's Syndrome when he was six years old. When Lewis started nursery he faced significant challenges and became very isolated as a result. Lewis was overwhelmed by stimulus like television, could not cope with any changes to his routine, and had significant challenges with eating which would result in him having to change his clothes after every meal. Lewis would frequently lash out.

Lewis attended The Yard with his family and it is there that they found out about Tailor Ed.



Tailor Ed provided Lewis with a range of support over a one year period. Tailor Ed helped Lewis to improve his eating skills and helped his parents to establish routines, such as fixed bedtimes. Tailor Ed staff helped by introducing a rewards scheme to help with his behaviour. The workers showed Laura that he did not use his left hand at all and they helped him with tasks to improve his co-ordination.

His mum, Laura, described how Tailor Ed **“really understood him”**.

- ✔ Lewis responded very positively to the 1:1 support that he received and this resulted in a huge improvement in his skills.
- ✔ Laura described how this also impacted Lewis's confidence – **“His confidence in who he was and in being himself grew enormously”**.
- ✔ His relationship with his parents improved significantly. **“It was a transformational point in his life and my parenting journey with him. I stopped seeing myself as a useless parent”**.
- ✔ Laura also attended parent sessions facilitated by Tailor Ed which she found highly valuable - **“It suddenly didn't feel like I was on my own”**.
- ✔ Laura was very positive about Tailor Ed's approach, the service not only supported Lewis but the whole family, and the workers included Lewis's younger sister by making her a chart to keep her involved.
- ✔ The service engaged with his school teacher to make sure she was aware of the approaches that worked best with Lewis.



“We are so grateful to Tailor Ed. We would recommend them to everyone in our situation”

Tom

Tom is 18 years old and lives with his dad, Dave. He lived in England when he was diagnosed with high functioning autism at the age of 3, but moved to Edinburgh when his parents separated. Dave contacted a child psychologist who he knew in Edinburgh and she recommended that he contact Tailor Ed, which had just been established. He feels very lucky to be one of the first families that Tailor Ed supported.

What issues did Tailor Ed help with?

Tom faced several challenges in his early years which provided signs that he might be autistic. A limited diet was one of these challenges and this was the first issue that Tailor Ed helped with, when he was 8 years old. His diet was largely limited to chocolate, crisps, peanut butter and toast, and there were certain foods that he would only eat in certain places or on certain days. For instance, he would only eat pasta, rice and chicken once a week when at a friend's house. Tailor Ed's support involved 26 visits over nine months and the approach included introducing Tom to foods from different countries and going on picnics while also making a film, in order to introduce Tom to new foods and to eating in new environments in ways that captured his interest.

When he was 10, Tailor Ed also provided support to help improve Tom's handwriting, which was messy and often unintelligible to the reader. This involved nine visits over two months and included various exercises to improve Tom's confidence and motivation to write more neatly.

What impact has Tailor Ed's support had on Tom and his family?

Tailor Ed's input on diet resulted in Tom being able to eat a variety of meals in different environments. Dave said that, with Tailor Ed's support, "we were always having this discussion with him, so he started being more proactive about his diet".

Dave and Tom were able to make further progress after Tailor Ed's support had finished and Tom's interest in food and cooking increased over the years, to such an extent that he now cooks a meal for himself every night. Dave said that "Tom's diet now is amazing".

There were also improvements in Tom's handwriting as a result of Tailor Ed's support, with improved ability, confidence and motivation to write more neatly.

Tom has recently finished his exams in mainstream education, and hopes to go to college to study film.

Tailor Ed's support also had a positive impact on Dave. He learned about different things he could do to further support Tom with his diet and handwriting, and how these techniques could be applied to other issues.

In addition, and importantly for Dave's wellbeing, the service helped him to feel better about his situation. Being able to chat to staff helped him to "get stuff off my chest" and "I got acceptance from them, that there's nothing different about having an autistic child".

Views of Tailor Ed's approach and ethos

Dave was very complimentary about Tailor Ed's approach. He said "they seemed to have great enthusiasm, they really wanted to make their mark", and he liked the way the workers spent a few hours playing with Tom to get to know him and his interests. He contrasted this to another service, which had asked Dave to fill in a lengthy form about Tom before holding a one hour meeting to discuss his responses.

Dave also described having to deal with many people "who didn't believe in autism" (including the Head Teacher at Tom's school), so he found it "liberating, just being able to talk to someone about your autistic child".

TOM'S STORY

Tom is 18 years old and lives with his dad Dave. He was diagnosed with high-functioning autism at the age of three. Originally from England, he moved to Edinburgh with his dad when his parents separated. Dave contacted Tailor Ed on the recommendation of a friend who is a child psychologist. Tailor Ed had not long been established, and Dave feels very lucky that he and Tom were one of the first families the organisation supported.



When Tom was eight, Tailor Ed supported him to improve what he ate. His diet was largely limited to chocolate, crisps, peanut butter and toast, and there were specific foods he would only eat on certain days in certain places.

Tailor Ed's intervention meant that Tom could eat a greater variety of meals in different environments.

Dave and Tom progressed after Tailor Ed's support finished and Tom's interest in food and cooking increased over the years, to such an extent that he now cooks for himself every night. Dave says that, "**Tom's diet is now amazing**".

When he was ten, Tailor Ed also provided support to help Tom improve his messy handwriting.

Tailor Ed's support improved Tom's ability, confidence and motivation to write more neatly and his handwriting got much better.

Tom is now 18, has recently finished his exams in mainstream education and hopes to go to college to study film.



- ✔ Dave learned about different things he could do to further support Tom in developing his diet and handwriting, and how these techniques could be applied to other areas of Tom's life.
- ✔ The service helped Dave feel better about his situation. Being able to chat to staff helped him to "**get stuff off my chest**" and he says he, "**got acceptance from them, that there's nothing different about having an autistic child**".
- ✔ Dave was very complimentary about Tailor Ed. He said, "**they seemed to have great enthusiasm, they really wanted to make their mark**", and he liked the way the workers spent hours playing with Tom to get to know him and his interests.

Chloe

Chloe, who has been diagnosed with autism and significant dyspraxia, began working with Tailor Ed in 2010, when she was 4 years old, and received intensive support over a period of two years. She and her parents have since moved to England, where she attends a specialist school for children with autism, and she is now 14 years old.

Chloe's mum, Katy, first heard about Tailor Ed when she saw an advert at the Yard (an adventure play centre for children with additional support needs). She decided to get in touch because "we were really desperate. Chloe was 4, she'd just been diagnosed with autism but her motor skills were a lot more complicated and challenging than most children on the spectrum".

What issues did Tailor Ed help with?

At the time, the family lived in a flat which could only be accessed by climbing 40 stairs. Chloe could not go up and down stairs and this caused problems for the family. As Katy said, "going out was a massive deal... terrifying – they were stone stairs... it was a real worry... we couldn't really get out quickly or safely".

As a result, Tailor Ed's first intervention was to help Chloe learn how to climb stairs. This involved arranging for a joiner to build a small set of stairs for Chloe to practice on, and working with her intensively one-to-one to teach her the skills and confidence to climb the stairs. Tailor Ed's support also included establishing a token system to build her motivation to listen and follow instructions, as well as the introduction of visual timetables to help her understand the sequence of events.

In addition, over the year before Tailor Ed became involved, Chloe's expressive language had regressed – she had lost her ability to talk. Consequently, Tailor Ed introduced Chloe and her family to the PECS system.

What impact has Tailor Ed's support had on Chloe and her family?

Tailor Ed's support helped Chloe to learn how to go up and down stairs. This was hugely beneficial for the family in practical terms: "Such a life changing thing for us and Chloe. When you can't go up and down stairs, you can't go to shops, you can't go to airports, you can't get on and off trains very easily".

The service also helped Chloe to improve various other skills. The introduction of the PECS system gave Chloe a way to communicate, which allowed her and her parents to communicate, and the token system "taught us how to motivate Chloe".

The focus of this support was on helping Chloe to develop 'learning to learn' skills that would help her to make the transition to school. Katy reported that the fact that Tailor Ed was able to help Chloe with these skills meant "she was much readier for school than she would have been... she would have been unable to sit down, keep quiet, keep still, no-one would have known what she wanted – she would have had no communication system... she would have been completely lost and the staff would have been completely lost".

As well as the progress that Chloe made, the support was hugely beneficial for her parents. Katy appreciated being able to see an expert from Tailor Ed at work and she reported that the skills and techniques that they learned from Tailor Ed have been “vital”. Katy said “We use all of these skills to this day... All those learning to learn skills are really useful for us now. If I think it’s going to be a tricky supermarket trip we have the token system, we have the visual timetable... we’ve been doing them for seven or eight years”.

Katy emphasised the importance of Tailor Ed’s support in developing her and her husband’s skills as parents: “[It] set us up for a lifetime of parenting Chloe. I still have their voice in my head when things are not going well or when I think I could be doing something better or differently”.

Tailor Ed’s support helped Katy and her husband to feel more confident about trying new things with Chloe: “We’ve always felt able to just keep trying things like going on a train, on a plane... [Tailor Ed] gave us the impetus to do that... However ambitious things felt, there was a way of breaking things down and doing it”.

Another benefit of the service for this family was it helped Katy and her husband to feel more positive about having a child with autism. Katy described feeling quite negative before Tailor Ed became involved: “Chloe was completely beyond anyone on the NHS that we’d come across” and she had begun to think that “maybe she’s beyond help “. However, Tailor Ed showed them that Chloe had “a huge amount of potential” and the ability to learn new things: “It put her into a different bracket of opportunity”.

Katy thinks that Chloe would be in a very different situation now if Tailor Ed had not become involved: “I honestly think we would have completely collapsed. We would have had a child that nobody would have known what to do with and the older she became the worse this would have got. Her behaviours by now would be so extreme that she would be in a residential school”.

Katy summarised the impact of Tailor Ed by saying: “They gave Chloe a childhood and they gave us the ability and the confidence to create a childhood for her”.

Views of Tailor Ed’s approach and ethos

Katy has an extremely high opinion of Tailor Ed and their approach to supporting children with autism and their families. In particular, she praised the following aspects of the service:

- The long-term nature of the service: “A target is set and Tailor Ed hang around until it’s met. What happens with statutory services we have worked with is you get given three or four sessions or it’s very time limited and then that’s that”.
- The tailored, individualised nature of the support: “There is no off the shelf assumption with Tailor Ed – everything is individualised”.
- The practical focus of the support. She described accessing support from other services to help teach Chloe about colours and shapes, but Tailor Ed’s support was focused more on skills that Chloe would need for daily life: “That’s the value of Tailor Ed – it’s working towards being included in the community and learning to learn skills that are valuable for the rest of our lives and for Chloe”.

- Low staff turnover: many of Tailor Ed's staff have been with the service for a substantial period of time, and Katy said this is unusual compared with her experience of other services. For example, Chloe has had around 36 teaching assistants and six different social workers over the past three years and so "none of them know her". The benefit of a low staff turnover is that "they have a deep working knowledge of the kids and the families... when you have a stable staff team... you can work with a family in 2012 and you can go back in 2016 and you can pick up where you left off... you're not starting from scratch".

Katy described Tailor Ed as "our gold standard". Chloe is at a leading school for autistic children in England but "we haven't found anyone better... Tailor Ed is extraordinary... a complete magic wand".

CHLOE'S STORY

Chloe, who has been diagnosed with autism and significant dyspraxia and is non-verbal, began working with Tailor Ed in 2010, when she was 4 years old, and received intensive support over a period of two years. She and her parents have since moved to England, where she attends a specialist school for children with autism, and she is now 14 years old.

Chloe's Mum, Katy, first heard about Tailor Ed when she saw an advert at the Yard (an adventure play centre for children with additional support needs). She decided to get in touch because **“we were really desperate. Chloe was 4, she'd just been diagnosed with autism but her motor skills were a lot more complicated and challenging than most children on the spectrum”**.



The family lived in a flat which could only be accessed by climbing 40 stairs. Chloe could not go up and down stairs and this made it difficult for the family to get out. Tailor Ed helped Chloe to learn how to climb stairs and introduced a token system to increase her motivation.

This was hugely beneficial for the family in practical terms: **“Such a life changing thing for us and Chloe”**.

- ✓ Tailor Ed also introduced the PECS system to help Chloe communicate.
- ✓ **“She was much readier for school than she would have been”**
- ✓ Chloe's parents learned new skills: **“[it] set us up for a lifetime of parenting Chloe... “We use all of these skills to this day”**.
- ✓ They also felt more positive about having a child with autism and they realised Chloe has **“a huge amount of potential”**.

Were it not for Tailor Ed, **“I honestly think we would have completely collapsed. We would have had a child that nobody would have known what to do with and the older she became the worse this would have got. Her behaviours by now would be so extreme that she would be in a residential school”**.

Katy spoke very favourably about Tailor Ed's support, in particular its non-time-limited, individualised and practical nature along with staff who **“have a deep working knowledge of the kids and the families”**.

“We haven't found anyone better... Tailor Ed is extraordinary... a complete magic wand”.

“They gave Chloe a childhood and they gave us the ability and the confidence to create a childhood for her”.

Peter

Peter is 14 years old and lives with his mum (Ellen), dad and younger sibling. He was diagnosed with autism when he was 3 years old. Another support provider initially supported the family after the diagnosis but Ellen did not find that support particularly helpful so, when her mum's friend told her about Tailor Ed, she got in touch and asked for help.

What issues did Tailor Ed help with?

The first issue Tailor Ed addressed with Peter was toileting. At this stage Peter was 4 years old, and Tailor Ed provided intensive support over a period of six weeks. The service tapped into his interest in Power Rangers to engage him and encourage him to use the toilet. As part of this, staff made a film that showed Power Rangers figures using the toilet. Ellen felt this helped to make it clear to him what he was being asked to do – “it was like a light going on in Peter’s head – ‘that’s what you want me to do!’”

When he was 6 years old, Tailor Ed helped Peter to get his hair cut, and at 12 years old, the service helped him to develop and follow a visual timetable to get out of bed and ready to go to school independently.



What impact has Tailor Ed's support had on Peter and his family?

Overall, Ellen said that Tailor Ed has been a crucial source of support for Peter since he first met them. The support with toilet training helped him to consistently use the toilet in different environments.

The input on haircuts made him feel more comfortable having his hair cut, and the more recent support with morning routines has helped to enhance his independence. Ellen said the support “really helped for his development” and has “given him a life”. She commented that Peter “believes in himself because they did”.

Ellen also reported that she and her husband learned a lot from Tailor Ed about autism and this helped to enhance their confidence and skills in supporting Peter. They have been able to use the techniques that Tailor Ed showed them to continue the progress they had made with the issues that Tailor Ed provided support with, as well as applying them to other areas: “because of the skills they gave us, we were able to implement our own plans”. For example, Tailor Ed was successful in enabling Peter to have his hair cut at home by a mobile hairdresser, but Ellen developed this further to encourage him to go to a barber shop.

Tailor Ed’s support also had a positive impact on Ellen’s mental wellbeing. She said that she was depressed when Peter was first diagnosed with autism and the family’s early experiences of other autism support services contributed to this. However, Tailor Ed “taught you to be positive about having a child with autism” and showed the family practical techniques they could use to address the challenges they were facing, and this helped to improve her mental health.

Ellen has recently gone back to work, and the increased independence in the mornings that Peter has achieved as a result of Tailor Ed’s support has helped with this.

Views of Tailor Ed’s approach and ethos

Ellen was very positive about Tailor Ed’s approach to working with children with autism. She said that Tailor Ed “take that time to get to know a child and family dynamics” and the workers are “incredibly gifted and skilled at understanding children with autism”. She thinks it is important that Tailor Ed, unlike other support providers she has experience of, recognise that all children are different with various motivators and abilities, and that what works for one child won’t necessarily work for another. She said it is crucial that the workers get down to the child’s level to play with them and get to know them. This, along with their kind and gentle approach, helps to gain the child’s trust.