

18 months report to Health and Social Care Alliance Scotland: Discover Digital Enabler grant.

Purpose of the award.

Tailor Ed Foundation was awarded a grant of £15,000 to cover an additional 15 hours staff time to enable us to expand our offer to autistic children aged 4 to 16 years and their families.

Background.

Tailor Ed Foundation supports 200 autistic children and their families who live in Edinburgh and East Lothian. Prior to covid-19 we had never even considered using digital resource to offer support. Then during the first national lockdown, without losing one days service we changed all our support to online. As the national lockdowns came and went, it became clear we had, as a result of this ongoing support, uncovered numerous barriers such children and their family faced with regards to digital interventions.

These range from lacking skills, confidence to consider using digital resources to some digital resources being unsuitable for autistic children.

This short report tries to capture our findings and learning over the past 18 months.

On reflection there have been three clear strands to this work:

- i) expanding our service offer using digital resources,
- ii) supporting parents use digital resources offered by other organisations,
- iii) enabling autistic children and young people to use digital resources

1. Expanding our service offer

Without doubt the strand which has seen the most significant changes has been the success of using digital services to support parents.

Briefly, our service offer used to be exclusively a home visit to work with an autistic child and their parent(s) to address daily living skills such as toilet training, communication, diet, sleep, emotional regulation. These visits would last for up to two hours and could take place as frequently as once a week.

For autistic children in their pre-school year this level of support lasts for 12 months and for school aged autistic children the length of time can vary from a few weeks to over a year.

One of the expected benefits appears to have materialised: some parents really love online support. In fact nowadays we have employed a remote worker who lived in

Belgium and recently moved to Liverpool so all her case work is delivered using digital tools.

Having spoken to parents there appears to be some very practical reasons behind this success. We have been told by some parents they no longer have to worry about a worker visiting them: they don't need to tidy up or clean the toilet!

However there is some growing evidence that parents that show more autistic traits prefer using remote services.

Furthermore by offering a remote services there are other practical benefits that have emerged. For example our staff are getting more "can I speak to you asap" calls. Working parents call during lunch breaks from their place of work rather than having to go back home to for a home visit.

There have also been some unexpected benefits.

Another helpful outcome from using digital resources has been parents training workshops. Our Early Years service has always provided workgroups to parents on topics such as what is autism, emotional regulation, preparing for Primary School. Whilst parents always find such opportunities really helpful, it was almost impossible to find a suitable location or time to deliver such training that suit parent's circumstances. Each year we support 35 young autistic children in their pre-school year and prior to covid-19 when we delivered parent training, attendance would be around 6 parents per session no matter where and when we ran the workshops. In the past 18 months when we have delivered similar training opportunities via zoom we have had attendance of more than 25 parents at any one time.

We have also seen an increase in parents and autistic young people who prefer video calls rather than telephone calls.

In particular we have noticed an uptake in parents wanting to do assessment and other initial processes via videocall, as well as the occasional meeting. Given many of the parents we work with are neurodivergent too, there seems to be a preference for videocalls over phone rather than a traditional telephone call, due to the ability of seeing someone's face and mouth moving while they speak (since this gives extra cues to understand what is said for parents who have speech processing difficulties). I have also had a couple of young people choose to meet me for the first time over videocall, it has been mostly young people who currently leave their home rarely and can find it daunting, and so the option of the videocall takes the pressure off.

As this approach helps us to build up trust with new parents or young people we have embraced this approach.

2. Supporting parents use digital resources offered by other organisations/sources

This is also an interesting strand as the feedback from staff and families whom we support has been more of a mixed bag.

The first factor is that we are getting far less requests for information from parents searching online for entertainment activities/resources for their children. Whilst this type of request was really high during the two national lockdowns when parents told us as they could not go out they were desperate to keep their children occupied and entertained. As society has got back to normal, parents are now planning activities for their autistic children which are all about running about and socialising.

Slightly surprising has been our experience of the use of digital resources by statutory services, especially schools.

Some staff are reporting really positive experiences: *“the majority of my CPM, YPPM’s meetings tend to be online and I think this is way more useful than in person meetings because more people can attend easily.”*

However other staff are saying some schools appear to be regressing back to pre-covid approaches where meetings with parents have to be face to face. *“I am definitely seeing schools being far less eager to talk online. They are demanding child planning meetings are in person.”*

This suggests there is an element of a digital lottery going on depending on which school parents use.

Following on from positive feedback from parents preferring digital resources such as videocalls or online platforms to register/use, our staff are being told by a growing number of parents they prefer this type of approach rather than using a telephone as it better suits their needs. Some parents have asked for help to initially learn how to use this digital approach and generally get the hang of it very quickly.