Hello and thank you all for coming today to learn about the What Matters to me project. I am mum to Aimee, who is 19 years old and has a profound learning disability alongside complex health needs. Aimee currently attends a special needs college in Eastbourne but will be leaving in July to what, we don't yet know. This is one of the reasons this project felt so important to us as a family.

Aimee has no speech. She is vocal but not verbal. She has likes, dislikes, interests and views just like all of us in this room. But for Aimee it is incredibly hard to get these understood. What has been really wonderful about this project is that Aimee has been the very centre of it right from the beginning. Taylor has been to visit Aimee at home and at college to get to know her and learn how she can best engage with her.

Most of all for Aimee, the project has been fun. She's been able to access experiences and activities that have been planned appropriately, are of interest to her and are completely accessible. We had an amazing swimming session with a group of Aimee's peers. She accesses swimming through her college but we are never able to take her swimming with her friends out of college time. As a family it is just too difficult and it's hard to find a pool that has appropriate changing and is warm enough for her. During this session the young people splashed around, interacted with one another and just had fun. Something everyone takes for granted but something that our young people are rarely able to do.

We also took part in an 'all about me' art project where we worked with Aimee to create a piece of artwork that represented her. Before the session Taylor spent time finding out all the things Aimee enjoys and ensured there were images, stickers and photos that she could choose from to incorporate into her piece of art. Aimee communicated amazingly during this session, primarily because it was relevant to her and had been planned in a meaningful way.

We also joined in with an interactive sensory story, where Aimee mainly communicated that she was 'finished' and that she didn't want any props at all. It was a really fun session and a great way to explore Aimee's thoughts and feelings, and just because those thoughts and feelings were that she didn't really want to be involved doesn't stop them being any less important or valid.

We had a fantastic session around story sharing with Nicola Grove. This session actually helped us as a family to think up new ways of talking with Aimee about past experiences and activities. It's difficult to know what Aimee does remember but thanks to this session we now have several photo books that we share with Aimee. Each photo book focuses on an individual trip out, occasion or holiday and it gives us the opportunity to chat with Aimee about past experiences.

It's so important for young people like Aimee to be heard and to be validated. When we talk about transition, we are talking about the start of their adult lives. Thinking back to when I was 19, I would have hated for my mum to have chosen what I was going to do and where I was going to live. That was my decision in the same way that these choices are Aimee's to make. The area where this gets tricky is working with external services, including healthcare, social care and education. Although we have had some wonderful experiences of working with professionals who have truly understood Aimee, the sad fact is that professionals don't seem to have the time capacity to get to know a young person and find ways to communicate with them. And often it's not that difficult. With Aimee symbols can work well, a professional knowing a few simple signs can be enough, giving her time and space before and during the appointment so she doesn't become overwhelmed all help to engage Aimee and make her part of the process. However, the want and understanding of the professional needs to be there.

Sadly, in our home town of Eastbourne, although consultations were held around the closing of a day centre, the decision to close the centre has gone ahead in just the last couple of weeks. Families understand that funding is limited in many areas but the young people attending this day centre have not been listened to, their views have not been heard and as a result their lives are going to be turned upside down and they will become even more isolated.

Services need to hear what is needed, funding needs to be appropriate and young people need to be engaged with at every step of their transition journey. Aimee has an older sister and the things I want for her are exactly the same as the things I want for Aimee. I want them to be happy, healthy, achieve their very best whatever that may be, to live somewhere they feel secure and comfortable, to be able to make choices and decisions, to have a fun social life and to be truly listened to and validated as young women.

When Taylor asked if I was happy to speak today, although it terrified me ever so slightly, I wanted to take this opportunity to share a bit about why this project is so very important. Our young people with complex communication needs are relying on you as MPs and professionals in your field to do your very best for them, to understand them and understand how to engage with them to ensure their lives are the very best they can possibly be. Thank you for anything you can do to make this happen.