

Email to the CMA from an individual who supports people with Rett syndrome and their families, carers and professionals

[redacted]. I am writing to you about the Tobii Dynavox (TD) and Smartbox (SB) merger.

I have so many thoughts I'd like to share but first I'd like to ask you one an important question.

Have you actually spoke to any of the people that use the products both TD and SB (and other companies) sell?? Now I'm not talking about the hubs (who buy the products to provide to people who use them and who only support 10% of most complex people who use AAC anyway), or the other companies who sell similar products. I'm talking about the people who use Augmentative and Alternative Communication (AAC) day in and day out? Who rely on it. And I'm not just talking about those who are literate e.g. people with MND who are literate and are already seen to be cognitively able and get access to communication devices. I'm talking about the large majority of TD and SB customers who are symbol-based users. Whose parents are fighting for them to have a voice. Are fighting for them to be heard. Have you spoken to these kids? Have you spoken to these families? I work with people with Rett syndrome. You may not have heard of it. You may think it's an insignificant market. And yet it's the second most common cause of severe disability in girls. Second to down syndrome, which I'm sure you will have heard of. About 95% of people with Rett syndrome are non-verbal and require eye gaze systems to talk. It's a lot of people. Our voices and opinions on this merger should be heard.

I think it would be helpful for me to give you some background. I am a qualified teacher. I have worked in both mainstream and special needs schools. I have a masters in Speech, language and communication. I also have a [redacted] with Rett syndrome. When she was first diagnosed, we were told she wouldn't walk or talk, and her understanding would always be at the level of an [redacted] year old. Thanks to eye gaze technology and products from companies like TD and SB she is now able to communicate. She is in a mainstream school. She is learning to read and write. This isn't something we initially achieved because of the government, because of public services. It's something we achieved in spite of them and their lack of help and lack of belief in her abilities. To get an eye gaze device through the NHS you have to prove you can use AAC. Well how can you prove you can use it without anyone giving you access and teaching you? You don't! So, it's thanks to these companies and charities like the ones I work for that so many more children and adults with complex needs are getting access to a voice. Thankfully once my [redacted] proved her competence, we were then believed and public services jumped in and helped and we have had good therapists and a supportive hub in recent years. But it took our own work, our own expense, our own trial and error to get to that point.

So, in order to get a true opinion on this merger you need to speak to these families that are going out alone. They are a very high percentage of TD and SB's clients. And these people, who you think you are helping through your investigation, who you think you're trying to protect, you are actually causing an absolute nightmare for.

I would like you to picture in your mind a little girl you know. Now picture that little girl with no voice, no hand use, they can't say anything. A little girl who without these products and the support

of these companies would not have a voice. Would not have be heard. Would not be able to get their medical needs yet. Would not be able to tell someone she was having a seizure. I want you to think about that image in your mind and see that this is not an Asda and Sainsbury's merger request. This cannot be dealt with in the same way (as your reports seem to imply they do, as so much of the wording is the same). This is a completely different industry. These are people's lives. People's voices. And you're messing around with them with your lengthily investigation.

I hope you are beginning to understand that this industry is very different to others you may be used to dealing with. That they need to be treated differently. I'm going to begin to explain some of the reasons why.

Firstly, I don't think you understand the impact the length of your investigation is having on people. I mentioned before that learning to use a symbol-based communication system is like learning another language. It's hard. And like with a baby learning to talk, the earlier you learn how to do it the easier it is, and the less time you are deprived of a voice. At the moment families are scared to make decisions about what to purchase. They don't know what's happening with the merger. They don't know what rash decisions you're going to make and so they don't want to make purchases. What if they buy SB software, then you make TD sell SB and the people don't keep on that software? Hours and hours of learning are lost. The family has invested in a system that will cease to exist. So, through fear of this happening they are instead not purchasing anything/not getting started. Hence depriving their child of a voice. Children are being left without systems because families don't know what to do because of YOUR investigation.

I read in one of your reports if the merger does not go through then you would make SB sell to an unknown buyer? Do you know how detrimental this could be?! You cannot have some random person running an AAC company who doesn't know about it. And even if they did you can not know what decisions they are going to make. They could dis-continue grid 3 and consequently take away people's language systems. People's voices.

Now lets talk about [X]. [X] is a [X] with Rett syndrome. She is very medically complex. She uses an eye gaze device to talk provided by SB. Charlotte uses a language system in grid 3. All the language systems in all the software are laid out differently. It takes a lot of work to learn where the different symbols are. And for someone with severe apraxia who is constantly fighting their body to achieve anything, they rely on motor planning. They rely on the words and symbols being in the same place. If someone took over SB and did not follow through with the language system [X] uses, you'd be asking her to start all over again. You'd be asking her to become voiceless and have to learn a whole new system to be able to have a voice again. She'd have to learn a whole new language. Let's say you learn Spanish. So you're really competent. You go to Spain (to a part of Spain that speaks no English, only Spanish). You've learnt it, you can communicate with everyone you can chat. You can get help if you have a problem. Great. Now one day you go to that same remote part of Spain and they've all learnt a new version of Spanish. They've changed Spanish. They no longer speak the version of Spanish you learnt. You no longer understand it. You no longer have the ability to speak this new version of Spanish. You have an emergency. You need to go to hospital. You can't explain to anyone because they speak this new Spanish. The Spanish that you have not learnt. You'd feel scared. You'd feel worried. You'd feel helpless. That's what you'd be doing with [X] who is very medically complex. [X] who spends a lot of her time in hospital. [X] who is currently able to explain her symptoms and problems so the doctors can put her on the best treatment plan. You could potentially be taking all that away from her. That's what you have the potential of doing to

these vulnerable kids and adults if you ask TD to sell SB to an unknown buyer. A buyer who could take away these language systems. I have no idea why you'd do that to people when you know TD is committed to grid 3 and committed to carrying on these language systems.

Now let's talk about prices!! You say you're worried that the merger and lack of competition could push prices up. I argue that couldn't be further from the truth. SB's software has always been more expensive than TD's. For the few weeks we thought the merger was going ahead, the families I support were all excited. Excited because we knew it meant SB's software prices would come down. Funnily enough in this time I was emailing with [X] about a software called 'Look to Read' SB had recently brought out. I'd been given a professional licence FOC so I could try it out and give feedback. Part of my feedback was that it was good, but just too expensive, particularly as schools have no money in their budget and families are self-funding. [X] replied and said he agreed and even said that one of things TD intended to do was to bring the price of products like these (products that support these vulnerable kids learn to READ and WRITE!) down. I hadn't asked him that question directly. He had no need to volunteer that information. He knows me well enough to know I am someone who will kick up a huge fuss and hold them to whatever is said. So writing that in that email. He would have truly meant that that was what was going to happen. We were all so pleased. Then I find out we're going to have to wait month and months for these price drops to happen (if ever!) because you've decided to investigate and are worried about price increases...the irony!!

Now, if this merger was the other way around and SB were buying TD. I'm not going to lie I'd be concerned. SB's software prices are higher, and I'd be worried they'd put prices up. But it's not that way round. TD (who could have higher prices currently given their current competitors prices are a lot higher on software)– have lower prices, and consequently I believe the merger will create a decrease in prices of SB's products.

At the end of the day companies like Microsoft and apple are getting into eye gaze. They're going to be TD's competitors and that competition is what will bring prices even further down. That's who you should be investigating as the competition. And obviously both these companies are wayyyy bigger than TD and SB put together!!

Next I want to talk about how difficult life is for families who use AAC. How exhausting their lives are. How everything is a fight. How they never have enough time in the day. And how the merger would make one thing a little simpler. Here's why. I know lots of people who are using TD's hardware and SB's software. For whatever reasons (and that's a whole other topic) it's what worked best for the person with complex needs they support. Do you know how much easier it would be for them if they're hardware and software came from one place? So that when something was going wrong you weren't having to try and deal with two different companies. Trying to work out if it was the hardware or software side of things that needed fixing. Trying to work out who's responsibility it was. Instead you could make one call. Get help from one place.

As far as I'm aware TD have guaranteed everyone at SB's jobs. At SB there is a lot of people in the support team. Support families desperately need. Support that would increase if SB and TD were working together. If an unknown person comes along, how do we know they're not going to see this as a money-making field, that they're not going to making lots of the support team redundant? Leaving these families abandoned. Because so many don't get support from the NHS, from the hubs, even from their schools. They're so often doing it alone.

We are so thankful for all the training days the AAC companies provide. To actually help people use their systems. Even AFTER they've purchased...you know AFTER they've already got the sale!! It's not

just about money for these people. They see a need to help. And you're limiting that with your investigation by taking time and resources away from these vulnerable people who need so much help. TD often run their training for free, while SB often charge £50 (still a reasonable rate), so again if they're together I only see it as a positive that the training around SB products would also decrease in price or become free.

In conclusion. I ask of you. Have you actually spent lengths of time speaking to symbol-based users and their families? The people in the 90% of AAC users who don't get hub support? The people that have to self-fund? The people that need and use these companies and rely on them for help? The people who you have spent too many months now leaving them in a vulnerable position not knowing what to do about their child's VOICE. I emphasise – they're voice – not just their groceries like a supermarket merger!

Please speak to us. Call me – [📞]. Come and speak to our families. Visit us. Let us have a say.

And please, whatever you decide about the merger, please do not enforce a sale of SB onto an unknown buyer who is not guaranteeing to keep everyone's jobs and the grid 3 software and all it's language systems because that has the potential to ruin so many lives of those with disabilities, effecting their human right to have a voice and be heard.

Submitted: 17 July 2019