

My sister's "ordinary life" **by Saba Salman**

My sister Raana recently made a film about her everyday life that was shown to an audience of 130 people at a conference in London.

This is a remarkable achievement by any standard. It's all the more impressive given that Raana, who travelled by train from Hampshire with her support worker and sat confidently in the conference auditorium, used to find public transport stressful and crowds overwhelming.

Although Raana still dislikes busy, noisy environments, gets unsettled at unfamiliar surroundings and finds communication tricky, the fact she made a film and shared it at a public event reflects what people with Fragile X and other learning disabilities can achieve - with the right support.

This latest episode in Raana's story of confidence and independence came about earlier this year, when she took part in the charity Stay Up Late's (Un)Ordinary Conference. It was "unordinary" because the day was about giving a platform to speakers with learning disabilities rather than professional experts. I was pleased – if a little surprised – when Raana said she wanted to apply to "speak". As she felt nervous about actually talking, she decided to submit a short film instead.

As for how this happened, Raana made the film and took herself out of her comfort zone with a trip to London thanks to her own determination and the unstinting and support of staff at The Lantern Community, Hampshire, where she lives in supported housing. Raana and her support worker Indra spent a day filming, both at The Lantern and in her local town centre. Smiling directly into the camera, Raana's film shows her catching the bus, doing her shopping, eating out and enjoying various arts and social activities. Raana might not have held the camera or edited together the shots - she had support to do that - but it was her decision to create the film and she decided what aspects of her life it should feature.

Raana was also reassured by the inclusive and relaxed nature of the conference, the accessible venue it was held in (my sister is not physically disabled but finds co-ordination difficult) and the collaborative, welcoming ethos at the Stay Up Late charity. In fact, she was so at ease at the event that she even took her cup of tea into the auditorium with her.

I wanted to share this story because when you have experience of Fragile X or other learning disabilities in your family, you spend so long arguing for support and articulating what your son, daughter, brother or sister needs, the disability – rather than the ability – can dominate your thoughts. We all know what people are capable of and can see their potential, but finding the right platform for that is not always easy. Securing the right support, meanwhile, is a battle amid cuts to special needs education and social care services.

A few days after the conference, Raana told her support staff she quite fancied go back to London for the day. While visiting the city is something she has done many times with her family, it has never been something she has wanted to do on her own, with support. Her request, directly linked to her participation in the conference, illustrates how encouraging someone's independence and confidence can spark more ambitions and goals. And long may that continue.

*Saba Salman is a social affairs journalist and regular contributor to the Guardian. Her forthcoming book, Made Possible, is influenced by her sister Raana and is available to pre-order. Saba is also a trustee of Sibs, the UK charity representing the needs of siblings of disabled people. She tweets at @Saba_Salman

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Links in order of insertion, in full

<http://thesocialissue.com/2019/03/my-ordinary-life-a-film-by-raana-salman/>

<https://stayupdate.org/the-unordinary-conference/>

<theguardian.com/profile/sabasalman>

<https://unbound.com/books/made-possible/>

<https://unbound.com/books/made-possible/levels/>

<https://www.sibs.org.uk/>

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