

Zara Todd presentation

Transcript:

Presenter:

Colleagues, I promise you we'll finish at 3.30 just before if anybody starts to panic, there's been one mobile that's been handed in to me if whoever's managed to leave it, if they want to pick it up from this desk on their way out and you could be forgiven from so far the programme today to think that [inaudible 00:00:22] wasn't interested in abuse of children and young people, I'm really grateful to those of you who have been involved in the interviews that the young people have been doing for us, but it seems fitting to be finishing the slot to hear from someone called Zara Todd who's had some extensive experience of some aspects of children's services, to share with you her own reflections on what worked and what didn't work for her, Zara, thank you.

The first thing I'm going to start with is an observation from Polly's speech, at the beginning of her speech, she mentioned indicators by Townsend of things that children should expect to do, which was to be able to go on school trips, to be able to go on holiday, to have access to the cinema. Now, for disabled people, regardless of their economic status, that list is a challenge and it remains a challenge and if you consider that a vast majority of disabled young people also fall into the poverty bracket, so that's something to think about.

Now, as you can see, I'm getting on a bit as far as a young person is concerned, but I'm here today because I've got the benefit of hindsight. I've pretty much been through the system and I can see what's worked and what hasn't. The other thing I would say is although I'm one person sat in front of you here, I've met hundreds, if not thousands of other young disabled people in the course of my life and although my stories are personal to me, having spoken to other people, there isn't that much difference. Unfortunately, and fortunately, the first thing I'm going to start with, obviously, as people in the UK, we all access services, everybody's life is touched by services in some way. Fortunately or unfortunately, for disabled young people, services are right in front of you from the moment go, you can't escape them and you're dealing with multiple services. You've got health, you've got social care, you've got education, everyone wants a bit of you. But the thing that often gets lost is everyone wants a bit of you, they want the bit that they are responsible for, that they can change, that their budget allows you to cover, but actually, you're an individual. So I don't want to think about how this falls into the health budget or this falls into the education budget, or this falls into social services, I just want to live.

Now, one of my friends uses a communication aid and unfortunately for her, she fell foul of the separation between services because education paid for her communication aid, so therefore it was decided that she wasn't allowed a communication aid outside of her school setting, now, what are you meant to do, sit there in silence for seventy five percent of your life because somebody decided that they weren't budgetary responsible for when it goes into your home setting? That doesn't seem fair, right or sensible to me because actually you learn as much about life outside of school as you do in school. So setting people up to be different categories really doesn't help, there needs to be a kind of holistic approach where you take account of the whole individual and you actually talk to one another, because a lot of the time, money is wasted by people replicating services because it falls into their budget.

So for example, I obviously use a wheelchair, however, this wheelchair wasn't provided by any service providers, nor would it have been when I was a child because according to the wheelchair provision aspect of my life, I don't need an electric wheelchair, however, if social services were involved in that assessment, they would probably pay for an electric wheelchair because it would be a lot cheaper than having to pay for the PA support that I get. Instead, the third sector or individuals had to pay for it. Now, this chair was eight and a half thousand pounds, now, it's lasted me about seven years, eight and a half thousand pounds over seven years is actually not that much money, if you think about the amount of care and support I would need had I not got my chair, I would have to have a PA with me constantly. Budgetary wise, it just doesn't make sense, yet, essentially the system forces me to cost more money if I hadn't been able to fund my own chair.

Services can be really, really threatening, obviously I'm an adult now, you guys don't scare me anymore, [laughs], but when I was younger, it was like going in front of a firing squad, everyone wanted me to focus on what I couldn't do, what was wrong, how they could minimise risk, not how I could live my life, what I could do well. Everything was about the negative, and for some people, services are really, really scary, by accepting services it's somehow society thinks you've failed or you've been negligent or you've somehow done something wrong, but actually services can be really, really helpful, but a lot of people have to deal with the stigma of accepting services and for disabled young people that is a pretty big deal especially if you're from an additional background which means, kind of, state intervention is even less popular and it's even more associated with somehow failing.

Not everybody is system savvy and that's a really big problem because those people that are system savvy tend to get a lot out of the system, but actually, and I know this might not be the greatest thing to say, they're not always the ones that need the system the most. And what scares me is I'm sitting in front of you now and I can talk in your lingo, I can talk about

common assessment frameworks and how to fill out a DLA form, but the question – I've been able to do that since I was ten or eleven, the question is should I have been able to do that? Should I know what systems you guys have to work through to get the support I need? I personally think I shouldn't know that and I shouldn't have known that as a child. Being a disabled young person in the system, you're forced to grow up, you're forced to become your own advocate even when you've got parental support, the number of meetings you get dragged into where you have to learn how to fight your case in a way that gets you what you actually need. I'm not asking for a swimming pool or a million pound, I'm just asking to be able to live.

Thresholds are a really, really big problem, now, as I've already stated, it's pretty obvious, I'm a disabled young person, I don't think most people would argue with you on the fact by the lovely wheelchair that I am sat in, yet I don't meet a lot of the thresholds in the area that I live and this is really dangerous because the threshold is set at kind of urgent and high level risk threshold, actually, if they were set a bit lower and it was preventative measures rather than emergency interventions, you would probably find you had less emergency interventions. The threshold is sending people to breaking point, it gets to the point where you have to have service intervention and you have to have major service intervention, whereas if the thresholds were lower and more sympathetic to the variety of people that are out there, you'd probably find that less money was being spent at the higher end of the spectrum.

And also thresholds again focus on the negative, what you can't do, what's going badly. Now, I don't know about you, but actually, it can get quite depressing if all you're ever focusing on is what you can't do, or the negatives and actually why should just because I'm a disabled person, why should my life be any more negative than anyone else's?

One thing that I would say is fighting for services often makes you feel like an outsider and so when you get services, you kind of, you don't necessarily feel comfortable, you're worried that someone's going to take them away or suddenly that if you suddenly do something that supposedly you're not supposed to that you'll be classified in some other way and everything will just disappear.

Parents that I've met are absolutely terrified, people expect that when you have a disabled child, suddenly there'll be this amazing array of support, but most parents that I've met all they tell me is "I've had to learn how to fight". I know people that have given up jobs just so that they can deal with the system and that doesn't seem right to me because it perpetuates the poverty issue.

On a positive note, I know most of what I've said hasn't been so happy, for me, personally, one of the biggest things that helped me and has made it a success, wasn't a formalised

structure, I was very lucky at key points in my life, individuals within the system, and I stress it was individuals and generally in their own time, took me aside and listened to me, found out what I wanted and explained the system to me, they didn't have to do that, but they chose to do that to help me because they could see that I had potential to achieve a lot more if I knew how the system worked.

As service providers, please be open-minded, be open to people, be welcoming, go out and find people, they're not necessarily going to come to you. Think about accessibility as wider than just ramps and physical access, it's about information, it's about attitude, it's about everything. Most disabled young people are not obvious, they're hidden, so you have to go and find them. And on the last note, remember, disabled young people are all of those titles, they are people, they are disabled, but they are also very importantly young and actually a lot of the time the system forgets the young bit. I've got my whole life to be a disabled person, I've only got eighteen years to be a young disabled person and that's really, really important, nobody should lose their youth because of the system.

[Applause]

Presenter:

Well, colleagues, with that Tour de Force, I think any questions might just ruin it at that point. I know you've faced a lot of challenges during your period of being a young, disabled person, by God you did something right, Zara, so, thank you so much for that.