

This is my story

Jayne Gallear





My name is Jayne, this is my story.

People who work at Changing Our Lives have written this story with my mum, Sandwell Metropolitan Borough Council and Sandwell Community Caring Trust, the organisation that supports me in my bungalow and employs my one-to-one support worker.

I'm 47 years old. I don't use words to communicate but that this doesn't stop me getting my point of view across. I am really determined and know my own mind. I am a very sociable person and I love to be around other people, but sometimes I like time on my own. I have a good sense of humour which has been described as 'wicked'.

I haven't always been in a position in my life where I can be independent and in the past people have labelled me as 'challenging'. However, in the last 14 years I've lived in my own home and over the last 4 years, I have been supported by a one-to-one worker, and this has enabled me to be an active member of my local community.

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Jayne was happy in school and in 1987 was the proud recipient of the school leaving cup. During all of Jayne's school years she was never labelled as 'challenging' or 'difficult'.

Then when she was 21, Jayne went to a learning disability day service. When she first started, Jayne was in a small group and seemed to like it. However, over time as Jayne was excluded from some of the activities, such as packing screws and 'work experience' type activities, and as staff and managers began to see Jayne as 'challenging', she became more and more unhappy.

She would be left alone and Jayne's parents felt at times she became quite isolated. She would sit in the foyer and watch people come and go and when she was really bored she would take great delight in going into the staff office and ripping up paper. Jayne's parents felt that Jayne was being excluded from activities done by the majority of people at the centre and singled out for different treatment. They felt that because Jayne didn't use words to communicate, staff and managers struggled to understand Jayne and misinterpreted her behaviour as 'challenging'.






This situation went on for several years. When Jayne was in a small group in the day centre she generally got on well with people, but when she was placed in a setting with more people this was difficult for Jayne. This was difficult for Jayne's parents too because they knew that Jayne was a sociable character and yet at the same time realized that she needed one-to-one support in most settings.

From when Jayne was 14 she had some time away from her family home at weekends in order for her family to have a break. Over time Jayne's breaks from home increased until Jayne was happy to be away from home most weekends. From age 14 to age 35, Jayne spent time away from home in a couple of residential short break centres. However, Jayne experienced the same difficulties in short break services as she did in the day centre; she was labelled as 'challenging' and staff treated Jayne with caution, expecting her to pinch, grab and pull hair. This was a very difficult time for Jayne and her family.





In 2000, it was decided that the short breaks centre could not meet Jayne's needs and that Jayne would benefit from one-to-one support in her own bungalow in the time spent away from her family. As a result a package of support was developed where Jayne was supported by Sandwell Community Caring Trust to live in a bungalow 5 days a week, and go home for weekends. This new package started in 2001.

Jayne's mum says, "The last 13 years have been the happiest of Jayne's life. She has her own home and she's got good people looking after. I have trust in the people that are looking after her and this makes me happy and it makes Jayne happy. She is now in the right environment with the right people around and she's treated like a human being. Jayne's staff encourage her to make her own choices and this is very important to Jayne. Jayne is a very determined and independent woman with her own mind. She knows what she likes and what she does not like and she communicates this, even if she does not use words. The staff at Sandwell Community Caring Trust know this and they have got to know Jayne's little ways over the years. This is why it works so well."






Just as Jayne's life improved a great deal from 2001 as she was living in her own home with staff she trusted, Jayne also began to have a better experience of day services. Managers in the day service recognised that Jayne needed a Communication Passport so that all staff within the service could understand how Jayne communicates and tailor their approach accordingly. Managers worked with Speech and Language therapists to develop a Communication Passport for Jayne.

They brought together staff who had known Jayne well and had supported Jayne over many years to discuss the Passport. These staff were encouraged to reflect on Jayne's positive and negative interactions and supported to look at how they worked with Jayne to embrace positive interaction and understand her better so any negative interaction could be understood and turned into something purposeful.

As a result with the correct level of support and understanding, staff in the day service enabled Jayne to express herself and this resulted in Jayne no longer needing to communicate or 'challenge' showing that she was unhappy.





In 2011 during Sandwell MBC's day services modernisation it was identified by managers that Jayne's day service within the community was not suitable for her as she needed more tailored and personal support. Meetings were held with Jayne's mom, Jayne and other professionals with the aim of Jayne going to a 'support plus service'.

Jayne visited the new service on several occasions and was clearly very unhappy about the service and communicated this very clearly in the way she behaved in the new service. To quote a staff member, *"Jayne definitely voted with her feet"*.

So in early 2012 Jayne received funding for a one-to-one support worker.





14 - Jayne Gallear - This is my story



Initially it was felt that this one-to-one support meant Jayne would no longer need to go to day services. However her parents were very keen for Jayne not to lose her friendships within day services.

Jayne is a very sociable character and thrives when she is with her friends so it was felt that if Jayne had lost this time with her friends in the day centre she would become too isolated. It was equally felt that over the years Jayne had benefited from a regular routine; Jayne had looked out of the window of her home every morning for years for the minibus to come and it was felt that if this routine was broken straight away it would be unsettling for Jayne.

As a result, the one-to-one worker and Sandwell MBC managers worked in partnership to look at the type of activities Jayne enjoyed and developed a programme that incorporated these activities. Jayne was given the opportunity to try new experiences and as her confidence grew so did her experiences.





It is very clear for Jayne's mom that having a one-to-one worker has opened up Jayne's world. Jayne's mom says,

"Sometimes being in a group can mean compromises have to be made and individuals lose out. Being in a group has been difficult for Jayne and it's always affected the way she communicates and behaves.

Having really skilled one-to-one support has made all the difference to her. Now she's treated as a human being and an equal person. As her mum I've always been afraid that there will be no one around to fight for her if I wasn't around. I have fought for Jayne since she was born. Now she's living in a bungalow and she has one-to-one support so I'm no longer afraid.

I know that she has a good life and I know that people within the service will always be there to fight her corner. I suppose my only regret is that we could've had this before. If Jayne had a one-to-one sooner she would not have half of the difficulties, she would not have been seen as challenging and many people would have got to know the real Jayne years ago."



18 - Jayne Gallear - This is my story



With the support of her one-to-one worker, Jayne now has an active life in the community. Jayne is part of a walking group; many of the people in this group are retired and all know Jayne really well. Sometimes Jayne goes to the brine baths; when she first started she would hold the hand of her support worker, but now she's much more confident and floats in the water on her own. Jayne also goes to the gym with one of her best friends she's known for years.

Jayne likes to do a bit of exercise then have a sit down, then get up and do a bit more exercise then have another sit down. Afterwards Jayne likes to wind down with a drink and a biscuit. It's important to Jayne that she gets to go out with her friend who she has known for many years because when they went to the day centre together they were inseparable.





Jayne also likes to go and spend time in the local library, leafing through the books and looking at the pictures. Jayne seems to enjoy the quiet time as a balance to the times when she's more sociable. However there are times when Jayne likes to make a bit of noise in the library and have a chuckle about this with her support worker.

Sometimes Jayne goes shopping and in particular likes putting things in the shopping basket herself and putting them on the checkout. Jayne's most recent achievement is scaling the local climbing wall.

When she was first shown the wall by her one-to-one worker, and staff within Sandwell MBC day services, Jayne seemed to have some hesitation and pushed the body hoist that people wanted to attach to her to one side, which clearly meant 'no way!' However a couple of months later Jayne was at the top of the climbing wall; nothing holds her back!





One of Jayne's achievements is travelling on the local Metro. Jayne had never travelled on any form of public transport over the past years as it was considered to be "too dangerous" and Jayne was considered to be "too challenging". However, staff from Sandwell MBC day services and Jayne's one-to-one worker, worked with Jayne incorporating what they had learnt from developing her Communication Passport and supported Jayne to go into town using the Metro. Jayne was thrilled with the experience and now travels regularly to different places via the Metro.

With the unstinting support of her mum and dad and the support of skilled staff, Jayne is now seen as a person first. All of the labels that have been previously attached to Jayne have dropped away and she is seen as Jayne; a cheeky, independent and determined woman.

Lessons Learnt



Individualised support

Individualised support, wrapped around Jayne focusing on her wishes and needs has worked well for Jayne. One of the reasons that this has worked is the time Jayne's one-to-one worker has taken to get to know Jayne and the way she communicates.



Communication

Jayne does not use words or any recognised means of communication (e.g. Makaton), and so Jayne's communication sometimes takes the form of behaviour. When Jayne was simply telling people she was unhappy through her behaviour, this was seen as 'challenging behaviour' and this label meant she was often isolated, treated differently and for some of her life demonised. Sandwell MBC Day opportunities managers worked with relevant people in Jayne's life to produce a Communication Passport, which tells everyone who works with Jayne how she communicates, both when she is happy and when she is unhappy. Creating a Communication Passport was vitally important as it enabled all people that worked with Jayne to better understand Jayne's very unique style of communication.



No one is too disabled

Staff supporting Jayne had the belief that no one is too disabled and that no one is too 'difficult' or 'challenging' to be part of the community. Sticking fast to this belief has meant that Jayne is now a member of the local community.



Bravery and taking risks

Jayne, Jayne's family and staff working with Jayne are all brave and have through working together learnt to take risks. When Jayne was labelled as 'too difficult' or 'too challenging' key people working with Jayne have been brave enough to take risks, and gradually over time this has resulted in Jayne having experiences of 'real life' in the community.



Partnership working

Staff and managers from Sandwell MBC and Sandwell Community Caring Trust worked in partnership to find what best works for Jayne. As with all partnerships those involved might not always agree on the best way forward, however 'sticking at it' and working through the issues has ensured that Jayne has a good life.



Changing Our Lives

22 - 24 Hagley Mews
Hall Drive
Hagley
West Midlands
DY9 9LQ

Telephone: 0300 302 0770

Email: ask@changingourlives.org

Web: <http://www.changingourlives.org>