



National Network of Parent Carer Forums

'Our Strength Is Our Shared Experience'

contact a family
for families with disabled children

Strengthening Parent Carer Participation

One parent's hopes for the future

Anna Walker, a member of the Parent Carer Council for Cornwall, tells us about her hopes for her daughter's future and why she is so committed to promoting parent participation



In 2006, aware of the intended government investment through the Aiming High Programme Anna invited the former CEO of Contact a Family, along with a member of the Treasury and the then DCSF, to visit Cornwall. She wanted to show them how the framework for participation (which had been achieved through the development of a forum) was impacting on the range and quality of services being developed and delivered locally.

Parents reported a huge range of additional benefits for themselves and their families and asked that consideration was given to the idea of enabling parent carers to be involved in the spend of the grants, and development and evaluation of services. This helped to secure the commitment

to invest in supporting the development and sustainability of forums across the England. Anna was until recently the SW regional representative for the NNPCF (National Network of Parent Carer Forums), a role she had undertaken since its inception in 2010. Susie is now 19 and Anna is still passionate and committed to remaining involved in all decisions that will affect her and to using her knowledge and experience to continue to help shape and improve services.

Anna Walker has been involved in parent participation for much of her daughter's life.

Here is a letter Anna wrote to herself outlining her wishes for her daughter's future.

"Susie is involved and at the centre of every decision made about her. Everyone involved in her life has made sure that they've taken the time to get to know who she really is."



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Dear Anna,

I just wanted to write you this letter to update you on what is happening here in the future and let you know that Susie-Jo is OK. Not just OK but really well. In fact, as I write this, she is sat next to me with a big watery grin, clutching her teddy bear Debra who is with her whenever she needs her, and who everybody knows is one of the most important people in Susie's life.

Susie is not living on her own. You were so worried about that, that she would be lonely and isolated. You knew that achieving this would never be easy because you had to work so hard to get people to share your vision and make it a reality. But it is a reality Anna, and she is sharing her home with some other young people who were already her friends. They make her laugh and feel safe and happy and are here to stay, just like Susie.

Susie has a wonderful team of people around her who really care about her. Every day she looks beautiful. She still has her long hair which is carefully brushed and styled, just how you used to do it and she's always dressed in the trendiest clothes, nothing is too much trouble.

Susie is involved and at the centre of every decision made about her. Everyone involved in her life has made sure that they've taken the time to get to know who she really is. They are so well trained and committed, and are proud and privileged to be part of Susie and her friends' lives. They know her so well and care about her so much.

Susie really is the author of her own life now, as her confidence to try more and more new things increases, so do the opportunities enabling her to make real choices in her life, not just the 'choosable' choices you and your fellow parents used to despair about.

Do you remember you used to say Susie would never have a job? Well you were wrong Anna. She works two mornings a week at a local café where the customers know her and come in especially to see her. She is so polite and helpful, her tolerance and acceptance of everyone she meets enables her to really shine in this role. You always said her strength was making people feel happy and important. It took a bit of persuasion and encouragement for everyone to really give her a chance, particularly to make sure she had the right amount of support to enable her do her job properly. But with someone taking on the role to really drive the vision, bring together lots of people to share their ideas and creativity, the commitment of a team of very dedicated practitioners and the hearts and minds of the local community we got there and Susie is so proud of herself.

And I'm so happy to say that has continued to be the case for the people who make all the major decisions about Susie's life. They have worked so hard to see who she really is with all her strengths, gifts and uniqueness, putting that before their protocols, budgets, processes and own agendas. They have all worked together to focus on what she can do and how they can best help her achieve her goals, no matter how small.

Matthew and Herbie often pop round to see their sister, they love visiting and often take Susie out for tea or on holiday. They are so proud of her and happy to know that she is OK and that they can trust those involved in her life and focus on their own. I know that you spent many, many hours lying awake at night anxious, frightened and desperate for everything to be OK. Despite all the support available through the



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years, having Susie at home was always the easy bit for you, it was the future you feared the most. Well you can relax a while now, breath out and look forward to enjoying some time for you and Mike. That final plan so many people worked together to achieve didn't end up just sitting on a shelf collecting dust, like so many previous plans had. This one has been turned into reality. It has given Susie a life.

Finally Anna I want you to know that everything you and all those parents that you worked alongside have achieved was truly worth it. Your passion and willingness to share your lives with so many has really changed the place disabled people have in our world today, changing hearts and minds, bringing people together and making the journey an easier one for future generations.

Reassuringly yours,

The Future



For more information about Cornwall Parent Carer Council for Cornwall go to
www.parentcarercouncilcornwall.org.uk/

Read more parent carer stories in Connected www.cafamily.org.uk/newsletter-signup/