

**PEOPLE
DOING IT FOR
THEMSELVES**

STORIES

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GARY THE STRONGMAN

Gary

Gary has lived in Somerset all his life. He has cerebral palsy which affects his balance and co-ordination. As a child he was a big fan of strongman competitions and aspired to get involved.

“I have been a fan since I was 6 and I said to my Nan one day I want to be a strongman”

At 16 Gary started to train with weights at his local leisure centre, an activity he really enjoyed.

“I always wanted to test myself and I don’t see my disability getting in the way of this. The only limits are the ones that you put on yourself. Everyone has the ability to contribute”

Gary became part of the GB powerlifting team and did weight training, but his interest was always in strongman. During this time Gary met Arnar Mar Jonson and 4 times World Strongest Man Magnus Ver Magnusson, who told him about their support for disabled strongmen in Iceland. Gary formed the idea to bringing Disabled Strongman to the UK.

“I asked to visit. They invited me to compete as the first UK Disabled Strongman in the world competition in 2011. I got an idea of how they did it and what was needed. I built relationships with the organisers and started a conversation about how to bring it to the UK”

Gary and Britain's Disabled Strongman Competition

But there was no provision for disabled strongman in the UK.

“There was no support, equipment or awareness of disabled strongman in the UK. Being part of the Iceland strongman scene, it was fantastic – the camaraderie, competition, it’s hard, its heavy, it tests you physically, mentally and emotionally”

In 2015 Gary set up a Facebook group and 10 athletes said they were interested in competing in a UK event. Buoyed by the positive response Gary decided to act.

“I got calling friends, family and local businesses. In 2015 we set up the first UK Disabled Strongman Competition, which was held at Stoke on Trent. It was a massive success with the guys from Iceland coming over to referee. Since then there have been 5 championships”

As well as the founder and promoter of Britain's Disabled Strongman Competition Gary is a coach and mentor for athletes with a disability in the UK and delivers promotional and motivational talks in schools, universities and colleges.

"I made it my mission to raise awareness and create provision in the UK and create a platform where other people with disabilities can have the same opportunity as me"

What helped?

Gary believes that having a strong drive and clear mindset is clear to his success. He has gained a great deal of support from his family, friends and local community.

"Being a Chard boy there was lots of local support, sponsorship and encouragement. The mayor gave us the hall for free. We had generous sponsors and people generally wanted to help. We had a lot of local builders who helped load, unload and set up the venues, we had local gym (Phoenix Fitness) that donate space and equipment. It was a real team effort"

Gary gained inspiration, help and support from Arnar Mar Jonson the founder of the Worlds Disabled Strongest Man. This has given him confidence, encouragement and motivation.

Challenges

A big challenge for Gary is raising sponsorship to cover the cost of hosting the national event.

"The local events are more successful as we could leverage relationships, favours and community spirit to make it happen"

Achievements and impact

From small beginnings the event has grown both in size and impact and has gained a national and international reputation

"In 2015 we had 10 male athletes. We now have over 20 male and female athletes and our event is now the official qualifier for the World's Strongest Disabled Man Competition. The last event in Chard was a sell out with over 350 people attending in the local Town Hall. It has put both disabled strongman and Chard on the map"

There has also been a huge impact on Gary personally and on other disabled people who are inspired by his story.

"Strongman and lifting is my life. It has given me a platform to compete and share my passion for Strongman. It has also allowed me to tell my story and show people that it doesn't matter if you have an impairment or not you can achieve things. It has enabled me to leave a legacy"

The future

Gary plans to develop the Disabled Strongman Competition in the UK and use it to forge connections and inspire other disabled people.

“I want to see Disabled Strongman Competitions in front of 10,000 people and on TV. I want to give people the confidence to try out strongman. We now have disabled strongmen across the UK, and we have a growing community of athletes who are training and spreading the word. Generally, I want people to follow their passions like I have”



ALEXANDER & AJP DREAMS

Alexander

Alexander lives in Scotland. When he was 1-year old Doctors said he would never walk, talk, read or write. As a child he went to special school but found it frustrating as it had low expectations of children and young people and didn't stretch them as a result.

“Mainstream kids choose their options, but special needs kids are only offered limited options”

At 15 Alexander was worried about his future. He had lots of aspirations but couldn't see how to make them happen. With the support of an excellent careers adviser he started to develop his skills and confidence and make links to people who might help including people at local charity Edinburgh Development Group (EDG). A person-centred planning exercise helped Alexander explore his strengths and to recognise and share his dreams including a wish to learn how to act.

Alexander spent time at a 'special needs' college on a pathways acting course but found it didn't stretch him. With the support of EDG Alexander began to explore other options, first on an internship as a development worker where he learned a lot about himself, then realising that self-employment might be a possibility.

“It was a light bulb moment - I thought....I could do this as a job!”

Alexander and AJP Dreams

With help from EDG, Alexander sought help from the Princes Trust where he enlisted on a business development course with Business Gateway and gained a grant of £250. From this early work Alexander realised he needed to develop his own skills and confidence if his business was to be a success. He found a second drama course where he worked hard to develop his body language and listening skills, voice projection and comic timing.

With his personal skills and confidence developed and early business planning completed Alexander, with ongoing help from EDG decided to launch his new venture. He gained help from several organisations to source funding, develop his business and to find customers.

Alexander now runs his own business called AJP Dreams. He uses his personal experience to inform and inspire others. He does this by delivering presentations, sharing his story, contributing to person centred planning work called Big Plan run by the Thistle Foundation and doing consultancy work across Scotland.

“I have gone from being a frustrated young man to be a successful businessman in a few, not so easy, steps. When I think back to where I started, I know it is all about determination and knowing when to ask for and accept help”

What helped?

Alexander is clear that getting the 'right sort of help' at the right time is key to his success (and to the success of anyone else considering making a similar journey). He is also clear that the journey to running your own business and/or living your dreams can be challenging but that important lessons are learned through overcoming these challenges.

"Even though I was failing I didn't give up...because I was learning"

Alexander gained help and support from many different people and organisations including Edinburgh Development Group (EDG), Rosie his careers adviser, Scottish Consortium for people with Learning Disability (SCLD), Nigel formerly from MiEnterprise and now a freelance business adviser. Alexander also gained help and support from his parents.

Challenges

Alexander was challenged by the fact that there were low or no aspirations for young people in special needs education. He also struggled to always get the right help at the right time on his journey.

Achievements and impact

Alexander has created the life he wants to lead. He has his own business which is established and sustainable and he is paid for the work that he does.

"Every couple of days I get a call from someone wanting me to do some work. I have changed my world a little bit at a time. I love my work"

He has helped other people to achieve their dreams and has made a difference to their lives. He is an inspiration to other disabled people and their families. A father of a disabled daughter said to Alexander's Dad 'Alexander is my Daughter's hero'.

Alexander is influencing people and organisations and having a strong impact as a result. A member of Scottish Parliament saw Alexander deliver a presentation and was influenced to question the wording of the Children and Young People (Scotland) Act away from 'care and cherish' and towards more aspirational language.

"I am helping other people and changing my world a little bit at a time"

The future

Alexander is committed to 'flamboyant dreaming' both for himself and other disabled people. He wants to do more work in this area to benefit himself and others. He has ideas for new presentations including one that challenges the perceptions of learning-disabled people.

"I finally know why, I am on this earth"



VICCI AND INCLUSION GLOUCESTERSHIRE

Vicci

At age 9 Vicci was diagnosed with a progressive physical disability. She studied hard and went to Bath University to study a degree in Business. As her studies progressed, she reflected whether she wanted to work for big business or do something with her knowledge and skills that would make a real difference in the community.

In her third year she did a placement in a charity which supports inclusive activities for disabled children. She developed an understanding of the gaps in support experienced by people with physical disabilities. She became determined to do something to try and address this issue. With budgets getting smaller and levels of need increasing Vicci could see that the voluntary sector needed to do more.

Vicci and Inclusion Gloucestershire

After completing her degree Vicci did 9 months of research and was then given some funding by the local council to set up a user led organisation for people with physical disabilities. In 2011 in partnership with other local, talented people, she set up Physical Inclusion Network for Gloucestershire (PING). PING offered information and advice to disabled people and quality checking services to care service providers.

In 2015 austerity resulted in a merger of PING and Gloucestershire Voices to form Inclusion Gloucestershire. Inclusion Gloucestershire offers support to people of all ages and all disabilities and Vicci is its CEO.

Inclusion Gloucestershire offers three streams of activity which include engagement, quality checking and development and training. Engagement includes hubs that run across the county that allow disabled people to drop in, spend time and engage in activities. Inclusion Gloucestershire also offers support to individuals looking to gain employment and a peer mentoring scheme helping disabled young people to aspire and plan for the future. Quality checking activity links to 3 contracts to quality check 180 care service settings annually. Quality assessments are done by experts with lived experience and action plans for improvement are created as a result. For the training and development strand of work information and ideas are shared in accessible ways through a drama group which meets weekly. This group builds the skills of those attending. In addition to this the organisation is commissioned to create films for training and education. Actors from the drama group participate in making these films. 12 videos have been professionally made for the N.H.S.

What helped?

Vicci and her organisation have been helped by supportive commissioners who were flexible and allowed passion and a good idea to be turned into something practical. This support along with some financial start-up funding got the ball rolling.

Support from contacts in other areas, sharing learning and good practice enabled Vicci to look at different ways of creating an organisation and ways of working.

Challenges

Austerity has resulted in a lack of funding at a time of increased demand. Competition for funding within the sector means that relationships can be strained. Local authority priorities change each year, new strategies are put in place. This means that the charity has to adapt their offer to meet the new objectives.

As an organisation Inclusion Gloucestershire and Vicci experience discriminatory attitudes. There is an assumption that people with disabilities can't be leaders. Vicci feels that individuals have to work twice as hard to show that they have substance and skill.

“It is great as a CEO of a user led organisation, with a disability myself, to have the ability to directly challenge those attitudes by my leadership role within my organisation”

The three 'disability communities' of those with physical disabilities, learning difficulties and mental health challenges all face different prejudices. The early perception was that these prejudices may be reinforced by them being associated together within one charity.

Achievements and impact

Having a growing organisation in difficult financial times is a real achievement as is successfully bringing two organisations together to create one team. Vicci is proud that 60% of her staff team have lived experience of disability. She is also proud that the organisation has grown but still held on to its values. The organisation has successfully created opportunities for disabled people locally - both staff and members. Vicci has also gained personal development opportunities.

“This has offered me professional development opportunities, which have included setting up a charity and governance, things which you just can't learn in a degree. It has also offered me personal opportunities to develop. My resilience has increased with my experience.”

The services and reach of the organisation expands every year to include more and more people.

The future

Vicci and her team have developed a three-year plan which includes carrying on their successful work, growing by 20% and developing their offer to young people. They also plan to develop more income streams through films and training and a leadership programme to up skill individuals with disabilities to become leaders. This will enable the charity to do more non-commissioned work and be more in control of its finances.



CLENTON AND COMMUNITY NAVIGATOR SERVICES CIC

Clenton

Clenton Farquharson MBE lives in the West Midlands. He made a connection with other disabled people, all of whom used health and care services and had a personal budget to fund the care or support they needed. Clenton and his peers felt frustrated by the health and care system and how it put processes and assumptions about what people need ahead of the experience and aspirations of the person themselves.

“ No one was really asking us what would help. What would be a great day? What would be a great life? I was fed up of people asking me about care. The majority of people want more than care and it felt as if local and national Government weren’t seeing that. You could say they were dampening our life choices by just seeing us as a set of needs.”

Clenton and Community Navigator Services CIC

Clenton and 2 friends decided to act, to use their negative experience in a positive way and try and make things better for themselves and others. They had the idea of establishing their own company to tackle the issues they had experienced.

“We thought about it for a long time. Somehow it was as if we were constantly seeking permission from those in power. Then we realised if we don’t do it nobody is going to do it”

Together they founded Community Navigator Services, a Community Interest Company (CIC) based in the West Midlands. They secured a small start-up grant from Awards for All and advice from a local organisation that helps social enterprises.

“Community Navigator Services CIC (CNS) is a user-led organisation with two key aims: to help people help themselves, and to support organisations change to become more accessible and approachable. We are passionate about social justice, and experienced in advocacy, training, coaching, mentoring, and communication”

Clenton also uses his experience and expertise to influence and effect change on the national stage. He is the Chair of the Think Local, Act Personal (TLAP) programme board; a member of the Coalition for Collaborative Care Co-production Group, a Trustee of In Control and Race Equality Foundation and acts as a Skills for Care Ambassador. In 2014, Clenton was awarded the MBE for services to people with disabilities.

What helped?

Clenton has a strong personal drive and a view that anything is possible. He has also developed strong peer networks and intentionally formed relationships with people in power in order to turn their scepticism into relationships and trust.

The start up funding grant from Awards for All played a strong part in the birth of the organisation as did advice and support from a local and national business advice services.

“In business this is what has helped us: being less predictable, purpose, networks, empowering, experimentation and transparency”

Challenges

Clenton and his colleagues faced a number of challenges at the start of their journey. They had no start-up funding or certainty of trading income and had to find the resources to ‘just do it’. They also faced bias from people in power about disabled people as business directors.

“Just because we are disabled it doesn’t mean we can’t run a successful business. We were constantly trying to break new ground as to how people saw us individually and collectively as a business. That was very hard as you would go into meetings and see people’s body language as they thought ‘this don’t compute”

Achievements and impact

Clenton and his colleague have created the ‘pursuit of confidence’ a tool that links to Direct Payments and gives people and professionals the confidence to have creative conversations.

They have also developed a peer support group called Better Lives Alliance with and for people who employ their own Personal Assistant (PA) and their PAs. The Alliance has developed an education programme which is framed around independent living and citizenship.

Locally Clenton and his colleagues have enabled people to change their lives. They have also played a part in a positive culture change within local authorities with professionals feeling more professionally safe to be creative and person-centred. For Clenton setting up Community Navigator Service with his colleagues has also given him a real sense of solidarity and modelling this to other people in a similar position also has impact on their lives.

“It gives me a feeling that I am not alone. It has given us all hope and the more people can collect around hope the better”

The future

In the future Clenton would like to help more people in different areas. He and his colleagues at Community Navigator Service are looking at different ways to do this.



WILLOW, WOMEN AND EFFECTIVE 'AUTIVISM' IN WALES

Willow

After 4 years and a long battle to have her condition recognised Willow, a proud Welshwoman, was diagnosed as autistic at the age of 44. Up until that point she had struggled to understand who she was and why she could not connect with people the way that others did. As a teenager, professionals believed Willow's daughter was experiencing challenges with her mental health. But Willow was convinced her daughter was also autistic.

"She presented in similar ways as I did when I was a child"

After another hard battle Willow's daughter also got an NHS diagnosis of autism.

Willow the 'activist' and campaigner

Following the poor NHS experience of her daughter Willow wrote a post on Facebook, expressing her anger and concern. The post had a huge response with people across the country getting in touch to share similar experiences.

"I realised it wasn't just me. It wasn't just my daughter"

The post became a Facebook group and the group started to link with autistic people who were campaigning for change. The Facebook group became a movement and the Autistic Women's Empowerment Project (AWE) was born.

Willow was conscious that her strong knowledge of autism gained from personal experience was not enough. She decided to undertake extensive training to enhance her knowledge.

Her activity brought Willow into the political arena and she was offered opportunities to speak about issues related to autism. Raising her profile resulted in people making contact. Willow helped people who contacted her and signposted them to sources of advice. This led to a growth in the network that continues to this day.

"When I first got diagnosed, I had 5 people in my network. I have a huge network now"

Willow and AWE have also worked alongside others to develop an annual autism conference for North Wales.

What helped?

In the early days Willow was supported by key third sector organisations such as Disability Wales, Autistic UK and AA Autism support.

“At the start I needed help to go to meetings. I can handle them on my own now”

She has also been supported by Mark Isherwood, Welsh Assembly Member for North Wales who is also the chair of the Cross-Party Group on Autism. Willow is helped to run AWE by her daughter, her friend Liz and by other members of the network.

Challenges

Willow has multiple, chronic health conditions that limit her mobility and ability.

“Finding the energy to do anything can be difficult”

Often Willow is asked to contribute to activity, advise people or speak at events free of charge. Currently Willow gives a great deal of time for free and funds activity herself.

“We are valued enough to advise people and speak at events but not valued enough to be paid for our time”

It can be stressful advising and supporting people, including those at crisis point, especially at a time of austerity when there are few services available.

“The Facebook group is going every hour of the day and night... you hear people’s very worst experiences. When you deal with people who are constantly in crisis it can really impact on you. I have to learn to build a protective bubble around myself”

Achievements and impact

Willow has developed a huge peer network of people who share and support each other. This has helped her to connect with other people and has led to self-awareness and self-acceptance.

“Having the network doesn’t just help other people it helps me as well. I now feel able to speak on a public platform”

Willow has contributed to the draft Autism Wales Bill and has become a Bevan Advocate. The annual autism conference is successful and now in its 4th year. Through her work the experience of autistic people across Wales has changed for the better.

“Things have changed...The Welsh Government are changing their language and engaging more. They are launching a national engagement strategy to connect better with autistic people“

The future

Willow would like to turn Autistic UK, a voluntary organisation for which she is on the board, into a sustainable CIC with secure income. She would like to set up a hub for autistic people in her hometown of Llandudno and establish an on-line resource hub for people from the autistic community.



CIARAN AND THE FILM CLUB

Ciaran

Ciaran lives in Warrington. He is a huge film fan and enjoys watching and reviewing films across all genres. He is a member of a local social group, talked to other members about his passion for film and told them that he would like to share his knowledge with others.

“I want to share my passion for film with the community”

Ciaran and the film club

He knew that watching films and buying drinks and snacks at a mainstream cinema is expensive and that this can make it inaccessible for people who don't have much money. He also knew from personal experience that going to the cinema can be challenging for some autistic people.

“In the cinema the sound can be very loud. When I was younger, I used to be really scared...I would put my fingers in my ears”

Ciaran thought that he could combine his knowledge, passion and experience to solve a problem faced by autistic people in his home town of Warrington.

“I thought that people with autism need their own film club. A safe space where people can see each other and enjoy themselves”

A few months before the start of the film club Ciaran had linked with a local project called Great Communities, run by charity MacIntyre. The project aims to support people to explore their passions and skills and use them to benefit their wider community.

“Pete (from Great Communities) and I had a discussion. I told him I would like to set up an autism friendly film club and he said he would help me”

Pete and Ciaran worked together to develop a plan, thinking through everything that would need to be done including finding a venue, getting the equipment, planning themes for films to be shown, finding club members and managing club nights. They identified a venue, a local community centre with a suitable hall and all the necessary equipment. Once the venue had been secured Ciaran began to learn how to use the equipment.

“I needed to learn new skills”

The club now has 15 members and is really successful. Ciaran makes no charge to club members and even offers refreshments free of charge in order to make sure the club is accessible even to people who have limited funds.

What helped?

Finding a venue that would work well for the club and already had the necessary equipment.

“It was a perfect venue. James showed me round. He helped me learn how to use the equipment”

Pete and the Great Communities project supported Ciaran to turn his passion into an idea and his idea into something real.

“Pete has been a great help”

Supportive members have also helped the club become an early success. The local Coop provide popcorn for club members.

Challenges

Ciaran faced an early challenge thinking through license issues and taking advice from a similar club in another area. Finding money to fund the venue costs was also an early challenge. Ciaran faced personal challenges that he has worked hard to overcome.

“At the start I found it hard to pick the themes and the films and to set everything up. It is a big responsibility”

Achievements and impact

Ciaran has had positive feedback from members.

“I think it has been successful. I got good turn outs. People said they enjoyed themselves and that they would come back”

He has learned new skills and gained confidence.

“I was very nervous in the first one but ever since the second session my confidence grew. I just introduced the film to everyone”

The club has brought people together and friendships have been formed. People who would not be able to afford to go to the cinema have been able to join in.

“Some people don’t have money. This gives them an opportunity to see quality films for free”

The future

Ciaran would like the film club to continue and develop with more themes and different genres of film being explored.

“I would like members to keep on coming. I would like to provide more insight into each film and build on the reviews”

In the future Ciaran would like to get a job working in the cinema.

“I would love to share my knowledge of film to cinema goers”

Ciaran and Pete from Great Communities have also come up with a new idea – to take the film club concept to other areas with Ciaran mentoring and advising film fans who might want to become film club founders.

“I could talk to them about it. I would like people to know what I have been doing. I could help them learn”



CATHERINE AND MHSCOT

Catherine

Catherine lives in Scotland and spent her early career working and volunteering within the 3rd sector. She saw first-hand the challenges people can face with their mental health and how ill equipped some employers are to support and enable their employees. Catherine also had personal experience of poor mental health and was personally aware of the struggles people and their employees face. She could see an opportunity to make a difference.

“Knowing the struggle of seeking employment after having lived experience of poor mental wellbeing and then hearing so many other employee’s stories about their struggles in the workplace I knew there was a huge problem that needed addressed”

Catherine and MHScot

Catherine decided to set up a new enterprise to tackle these issues. She could see how a social enterprise could offer employment and work opportunities to people with experience of poor mental health, herself included, so decided to structure her new enterprise in this way. The social enterprise which Catherine founded is called MHScot Workplace Wellbeing. The organisation is also a Social Firm.

MHScot operates across Scotland and works with businesses and enterprises within the private, third and public sectors. Most of their activity has a focus on training and education and they design and deliver training programmes and workshops for teams of staff. They also offer consultancy for employers to help them create a healthy workplace that is able to support the wellbeing of its people. They help organisations review their policies and operating practices and to make changes as needed. They undertake staff surveys and audits in order to help employers learn from the experiences of their staff.

“We help individuals and businesses face the problems created by mental health issues and attempt to change the way these issues are perceived, understood and dealt with”

The organisation has a small core team of employed staff combined with a wider group of Associates who do work for the organisation as and when required.

What helped?

Catherine gained a place on the School for Social Entrepreneurs development programme, a year-long programme offering learning opportunities, mentoring, connections to support and grant funding. This gave her the information and confidence she needed to develop MHScot. She also gained support and information from Social Firms Scotland and the Edinburgh Social Enterprise Network – where she continues to contribute.

Catherine gains invaluable support from the Access to Work programme – a Government funding stream which offers people the financial and practical help they need to work.

The way MHScot is structured helps Catherine and her colleagues. Catherine is clear that MHScot is a healthy workplace which offers people the work patterns they need to manage their mental health at the same time as working and contributing their considerable expertise and skills. People are offered part time work opportunities and/or work hours and conditions that fit with their life and health challenges. The organisation refuses to be drawn into deadlines and responses sometimes required by their customers.

“Sometimes people say they want a response to their e mail by return. We challenge this and help them to see when they are creating stress that isn’t really necessary”

Catherine gains personal and practical support from her Husband and this enables her to manage the work/home balance required to run MHScot.

Challenges

Catherine faces physical health challenges which can mean she tires easily and finds travel difficult.

Catherine is regularly assessed for her entitlement to Access to Work funding – this is a real challenge as without this support she would be unable to run MHScot.

Achievements and impact

Catherine and MHScot have developed the 'Workplace Mental Health First Aid Programme'. Alongside this they have developed a successful partnership with Apex Hotels – delivering the Mental Health First Aid Training to their staff and members of the public. They have trained over 1100 people on various mental health and wellbeing courses and workshops, having a huge impact on their knowledge, understanding and work practice. Employers and employees regularly feedback the positive impact of the training they have undertaken.

MHScot won 'Best Employee Mental Health Support Service' in the 2018 Scottish Enterprise Awards.

Catherine is clear how improvements in the workplace can have much wider impact on people, their family and community.

“Problems in work resulting from mental health issues have financial, health, social and economic consequences for individuals and employers alike”

The future

Catherine plans to consolidate the work of the organisation – to maintain its activity and impact without growing too much. She wants to help more people but to do this in a way that maintains the wellbeing of herself and her staff and Associates.



CHARLIE AND HER BEAUTY ZONE BUSINESS

Charlie

Charlie is a young woman who lives in Rotherham. She has a passion for beauty and real skills in beauty therapy.

“I always enjoyed doing make-up, people loved coming for my massages, because I’m so good”

On leaving school she studied hard and achieved several beauty therapy qualifications.

Charlie and Beauty Zone

At first Charlie volunteered as a beauty therapist and offered her treatments to friends and family. Charlie has autism and when she decided to progress her interest into a career, she found that despite her obvious talent she was not able to get any opportunities.

“I looked for a salon job and nobody would take me on or give me a chance because of my disability, even though I am hard working. Therefore, I thought I might as well set up my own business”

Charlie’s Beauty Zone is a beauty therapy business based in Rotherham. Charlie offers a fantastic range of treatments including manicures, pedicures, tinting, makeup and massage. She offers her services to the public but also does tailored work with carers and other people who may find it hard to access mainstream beauty therapy.

“It is nice to see people with disabilities enjoying a bit of pampering, because I think it doesn’t matter if you have a disability, I think you should always have a bit of pampering, get rid of stress.

They just come to me because they know they can be nice and relaxed, if they want to talk they know I’ll listen to their troubles, it’s like they get a bit of counselling, but they know it won’t go any further, it stays in the room... I’m very professional in my job and they know they can trust me”

What helped?

Charlie began to work with Speakup a local self-advocacy service in Rotherham. People at Speakup introduced her to Harry at Community Catalysts because they thought he might help her to turn her passion for beauty therapy into her own business. Harry from Community Catalysts offered Charlie help and advice as her idea developed into an enterprise.

“Even though every company should let someone apply for a job with autism I’ve found I’ve always struggled to get a job, so soon as I mention autism, they say what’s that. So that’s when Annie (at Speak Up) put me in touch with Harry and then we looked at the business thing”

She has had lots of help from family and friends, both practical and personal.

Challenges

Charlie is clear that setting up your own business can have real challenges and be stressful as a result. It can also be hard work and sometimes unpredictable.

“It is hard work, I love the business, but sometimes people can text you one minute, like on a Sunday wanting me to work, I can’t do it”

Achievements and impact

Gaining her beauty therapy qualifications was a real achievement for Charlie.

“Finishing my level 3 in beauty. Because when I was younger, when I did my level 2 got told I wasn’t capable of doing it they said it would be too difficult, but I always like a challenge”

She has built up a strong client base and this is growing all the time. The high standard of her work is evidenced by how many regulars she now has returning for treatments. Charlie has gained skills and confidence along the way.

“I can put a lot of things down on my CV, I can put management down I can put reception down, I can put bookings down. I have more confidence because, it’s just shown that I can actually work in a salon”

She has also had a positive impact on carers and disabled people in her community who use her services.

“Parents and carers often find it difficult to take time out to treat themselves and many would never feel comfortable going into a Beauty Salon, as they would feel intimidated by the environment. Charlie now spends a full day once a month at the Forum premises offering beauty treatments at a very reasonable cost. Her customers have reported back that they find Charlie very easy to get along with and the fact that they can book to have treatments in an environment they are familiar with, makes a huge difference. Working with Charlie has been incredibly beneficial to us, the Forum are looking forward to a long-term working relationship with Charlie” - Andrea, Rotherham Parent Carers Forum

The future

In the future Charlie is hoping to have her own beauty therapy shop.

“I’m hoping I can afford to run a shop instead of being at home because, then as soon as I walk out of the door, I know that this is my responsibility. I just want to work for myself... to be the boss... because I know if I work for myself, I can do things when I want.”

STEPHANIE AND VISION THROUGH SOUND

Stephanie

Stephanie is blind and worked as a computer programmer for 20 years before training as a rehabilitation worker for newly blinded adults. Through her work she found herself sharing information about the technology she used with other people. When she was made redundant, she decided to take her skills and knowledge and use it to help others.

“I wanted to help blind people and wanting blindness to be an asset rather than a hindrance. I developed repetitive strain injury in both wrists, which meant many things I used my hands for caused pain, including reading Braille. I was devastated, as touch is of incredible importance to a blind person. Yet I knew that God loves me, and put me on this earth for a purpose, He could also give me the power to forgive those who put obstacles in my way. Bit by bit I discovered using my strengths, rather than looking at my weaknesses, using what I can do, rather than what I can't do, has made a huge difference to me.”

Entrepreneur and change agent

Stephanie established a Community Interest Company (CIC) 2 years ago. She teaches blind people how to use technology to improve their life and give them skills to do what they want to do. She helps people access technology such as talking computers and phones that speak. She also leads the development of new equipment and software and explores ways to use existing technology in different ways. For example, ‘talking beacons’ which use a phone app to inform blind people which shop or building they are about to enter. Stephanie advises on information and accessibility, helping organisations who want to ensure their website is accessible and creating braille or tactile information for councils.

Stephanie also does a lot of work to open opportunities to blind people who live in Zambia, with an orphanage, school and group of blind adults.

“I found them portable solar powered bibles in their own language, and they were over the moon... I learnt so much by going over there, because most of the equipment that we have won't work over there, because they've got nobody to repair it, they've got no electricity to run it...so to have solar powered was just what they needed.”

What helped?

Stephanie has a guide dog who is key to much of her independence. In addition, the Government Access to Work scheme provides Stephanie with financial help to work and to run her enterprise. She uses the money to pay 3 different assistants each of whom has a very different skills set.

“I couldn’t do any of this on my own...they provide 12 hours a week of help from a sighted colleague...to do all the things that I can’t do without sight, like mainly filling in print forms, and driving, things like that.”

Stephanie gained help from Community Catalysts, Business Start-up at Bromsgrove Council and social enterprise development agency Blue Orchid who offered business advice and helped her secure a small start-up grant.

“Community Catalysts has been a great boon to me, because Christine really understood, and was prepared to listen to what I can do and support that, where so many previous start-up schemes that I had been on were trying to fit me into the box...”

Stephanie is a Christian which motivates her, and she has been supported by her Church.

Challenges

Stephanie has been challenged by the low expectations of others.

“I think sighted people had low expectations of blind people, and of disabled people generally, and I’d been discouraged”

Stephanie found setting up a new Community Interest Company and other activity that involves form filling and paperwork very challenging.

“It’s such hard work and the forms are an absolute nightmare. It took me a good 2 months to fill them all in. Paperwork is always a problem, even the lottery funding, the form was difficult to fill in, I could do some of it online using NVDA Non-Visual Display Access, where the computer talks to me but that didn’t always pick up everything on the form...”

Achievements and impact

Stephanie is a strong role model for blind people in the UK and Africa.

“I’d always wanted to go to Africa for ages and I thought...because of being blind I would be more trouble than I was worth, but now that I have found blind people that really need my help, and the effect of having me over there... I don’t have to say anything, just by standing there, I’m proving that a blind person can do things, it gives them hope, it’s quite dramatic”

Starting her own enterprise and working to help others has had a hugely positive impact on her personally.

“It’s made me easier to live with, you know when you are comfortable with yourself, and you don’t feel the need to prove that you can do it, and you’re not fighting people all the time”

The future

Stephanie is leading a project on the development of the User Interface Braille Kindle, the Canute from Bristol Braille Technology. She has taken it to schools and to groups of blind individuals all over the country and found 50 potential customers for a project that will shortly be available for public sale.

“People will be able to read thousands of braille books in one machine rather than having piles of books all around the house...I’ve been instrumental in developing the user interface and designing how the user can operate it...”

In the future she plans to provide technical support for this machine from home and also take it around the country to sell it to people.

ROBERT THE INFLUENCER AND CAMPAIGNER

Robert

Robert has lived with a chronic condition for many years and has had rheumatoid arthritis since he was 3 years old. He has been a wheelchair user for much of his life. At University Robert heard about people using transcendental meditation to help them with stress ahead of exams and thought he would give it a go.

“It did far more than help with exams...three years later I came off all my medication. I had been due joint replacements around that time but no longer needed them and haven’t had any since. I have self-managed my condition since then”

Soon after Robert realised other people may benefit from self-management and started volunteering. He worked with a West Lancashire group for disabled people and Arthritis Care, a national charity where he began campaigning work.

Robert as an influencer and campaigner

From his volunteer and campaigning work Robert became involved in the setup of the Coalition for Collaborative Care (C4CC).

“At the beginning there were 28 people in the room all at the receiving end of the care system. All had so much to offer”

C4CC are now a major influencer at a strategic level, working in partnership with NHS England and others to make health care and related supports more personalised. They are guided by the experience of people with long-term conditions and have a strong focus on coproduction.

In addition to his work with C4CC Robert voluntarily represent peoples with disabilities and chronic conditions locally, nationally and internationally. He is a patient advocate board member for 3 charities including the Healthcare Quality Improvement Partnership (HQIP); the International Foundation for Integrated Care (IFIC) and the European Forum for Good Clinical Practices (EFGCP). He also sits on the board of an organisation who support work and education options for people with disabilities.

“At their (IFIC) recent conference 1500 people from around the world came together to talk about care, and patients are the central point in that”

What helped?

Robert's own personality, skills and dedication have helped him to 'do it for himself' and become an advocate for others.

"Having got the self-management skills, I was able to transfer them over to other things"

The Coalition for Collaborative Care started very locally with the Council for Voluntary Services overseeing and helping Robert and other members of the group with the set up.

Challenges

The main challenges Robert faces are physical.

"Physical challenges are part of the battle. At conferences you have to ask for them to pay for a comfortable seat or a night at the hotel before the meeting. Sometimes even the NHS say they can't pay for an overnight stay. Sometimes there are policies that say expenses can only be paid out for public transport, but I can't just hop on a tube and sometimes I need a taxi"

Robert also highlighted the challenge of funding and how it is affecting some of the groups he is involved in.

"[The co-production team at the] Coalition for Collaborative Care are not funded anymore. It was about all the people with lived experience coming together and now that has ended."

Achievements and impact

Having his views being listened to and being in a position to influence positive change is an achievement for Robert and he can see the impact this has.

“I’ve had the opportunity to lobby MEPs and helped to raise awareness of problems that people with arthritis might have. The doctors, doing the lobbying at the event, were really surprised when the MEPs were more interested in talking to the patient than them”

The work also has a positive impact on Robert and his life.

“It’s those sort of things that have given me a psychological lift. I’ve also had as much learning from this as a traditional career and I’m much more confident in all areas.”

The future

Robert is currently looking around for other opportunities and avenues to be involved in since the funding has ceased at the Coalition for Collaborative Care.



LOCAL SOCIAL CIC

James, Karin and Andy

James, Karin and Andy all live near each other in Hertfordshire. James and Karin have learning disabilities; Andy has personal experience of mental illness and is a Shared Lives carer and Shared Lives Plus carer Champion. James lived in residential care for most of his life until he went to live with Andy and his family in a Shared Lives arrangement. More recently James has moved into his own home, but he and Andy continue to share their lives together. Karin lives locally and knows James and Andy well. James, Karin and Andy felt there was something missing in their local area - a lack of opportunity for people to connect with each other.

“I wanted to meet other people and make new friends and become more independent. I like to help other people” - James

The trio decided to work together to set up a new venture.

Local Social

Local Social, a new social enterprise and Community Interest Company (CIC) was established in April 2016 in Ware, Hertfordshire. The main aim of the new venture was to forge bridges between communities by getting people to interact. James and Karin were also hoping the new venture would open opportunities for them – James was particularly interested in making friends and gaining paid work.

“We wanted to do something that gave James and Karin the chance to meet new people, but also provided a wider benefit to the local community.” - Andy

Initially, they used a local office space, but now operate Local Social out of a café/community space. They provide free drinks and an opportunity for local people to come and chat. They have also recently started hosting a get together in a local pub once a month. James and Karin are supported by Andy to run Local Social, and over time they have taken a more active role.

“I help facilitate it, I am a conduit for their ideas, experiences, words and enthusiasm. But Local Social is all theirs and over time they are getting more and more involved. James, Karin and I are here early in the morning to set-up” - Andy

What helped?

Key to the establishment and success of Local Social has been a real desire by James and Karin to get involved, be social, make new friends and become more independent. Andy's support to help James and Karin to realise their ideas was also essential.

Local Social has been helped by the goodwill of local organisations/ companies, such as the Country Market where they run the Local Social café and a local pub that allows them to host events. It has also been helped and supported by local people and community organisations such as the CVS.

“None of this would be possible without the goodwill of the community. We've received donations, advice, help and support and people from all parts of the community. The young, the old, people with children, come here to spend time and talk with each other” - Andy

Challenges

Initially the trio were uncertain about the business model of their new venture and how best to set up a CIC. Managing the organisation, including the necessary administration has also been a challenge especially as none of the founders had business experience. Expanding the scale of the activity and attracting more funding was also a challenge.

“We learnt in the end that you had to start fairly small. At first, we went for big pots of funding, but this was a distraction and not successful. You don't need a lot to start. Once you start doing it, people and funding and support will come to you. But our biggest challenge now is the management and administration of it all and wanting to take it to the next level” - Andy

Achievements and impact

Setting up the CIC is a real achievement as its success in engaging and connecting people. The trio have had lots of positive feedback from people in their community. Local Social has helped James and Karin become more confident and independent and has improved their health and wellbeing.

“I like helping and talking to people. I am more independent now” - James

“When my mum died, I didn’t want to leave the house. But this gets you out and you meet people. I like coming here. I like to talk with people. It is nice to meet new people” - Karin

Local Social has also provided a means for different parts of the community to come together.

“The aim was to increase community connectedness and provide a space for different people to meet each other. You can see looking around that there are lots of different people here, all interacting. There’s a positive atmosphere. So, it’s doing what we set out to do ” - Andy

The future

Local Social want to carry on, getting more people involved.

“We want to advertise to get more people to come here” - Karin

They want to run more workshops to share their stories.

“We want to tell people about what we’re doing and how it can help them” - James

They want to also extend the reach of Local Social and have a vision to work with other organisations, such as the Isabel Hospice Compassionate Neighbours Scheme.

CARL AND CHALLENGING PERCEPTIONS

Carl

Carl is 25, has personal experience of mental illness and gaps in services and support for children and young people.

“I saw a big gap in mental health services and support. You can train in mental health and if you’ve experienced it you can help people with it”

Carl is the Chair of the Board of Directors for a community hub called Park Lane Centre.

“The Centre Manager approached me and said ‘we want a young person on the Board of Directors’. I attended a meeting and the Chair asked me to join. I served as a Director for 2 years and was elected as Chair”

Carl and Challenging Perceptions

Carl was approached by a Governor for South Staffordshire and Shropshire NHS Foundation Trust who was also aware of gaps in services and support for young people and thought Carl might be willing and able to set up a peer support group for 14-18-year olds.

“At first it was scary ‘cos I didn’t know what to do. So, I asked the community and we came together and set up as a community group to support each other. After about a year things started to really take off, and I could see we were closing gaps in needs.”

Over time the group evolved into a small community business and Community Interest Company (CIC) called Challenging Perceptions, run by Carl. Challenging Perceptions evolved its activity into advocacy, then added peer support groups.

“It wasn’t until I got to start meetings with young people that I realised there was a need for advocacy that I set up this service.”

Groups are well attended with the young person’s group having approx. 50 members and the newer adult’s group approx. 30 members. Challenging Perceptions is run by its members for its members with people deciding the work priorities and direction of the organisation.

“They lead. I make sure everything run smoothly and all the legal stuff’s sorted”

Challenging Perceptions aims to change the perception and experience of people living with mental illness.

“Our mission statement focuses on tackling the stigma associated with mental health and discrimination. I want to work with others towards making good mental health the norm and increasing access to the quality services and support whenever people need them.”

He now co-chairs the Telford Mental Health Forum, contributing to the development of the local mental health strategy and involving people from Challenging Perceptions.

What helped?

Carl’s involvement at Park Lane helped his development of Challenging Perceptions.

“Without the support of Park Lane Centre none of this would have happened. My confidence wouldn’t have been there. The Centre has been like a family to me. So, by joining, without confidence, there’s no group and no support for the young people – it’s like a domino effect really”

Carl was supported at the start of his journey by the local NHS Foundation Trust, Telford and Wrekin Council and Community Catalysts. He networked with people running similar social enterprises and learned from them. Carl is clear about the benefit of networking and grateful for the support and encouragement he receives from people who challenge perceptions of their own lives, his groups, and other organisations like the CVS and the Telford Mental Health Forum.

Challenges

At the start Carl found it hard to find the information he needed to form and constitute his group into Challenging Perceptions.

“There’s information on the net. But I wasn’t sure whether to stay as a community group or set up CIO, a CIC or a charity.”

Carl rises to the real challenges of running Challenging Perceptions on his own.

“The biggest challenge is the fact it’s all voluntary. I’ve got great volunteers helping me to run groups. On the management side I have enjoyed learning about running accounts, applying for funding and managing the risk that comes with leading a socially responsible CIC that wants to help people for years to come.”

Carl has had to work hard to gain funding for the work Challenging Perceptions undertakes.

“All income comes from writing solid applications, which allow Challenging Perceptions to deliver successful outcomes from high impact projects. Every penny we invest in these projects is won in competition with others from much larger organisations, like Telford and Wrekin Council, the Big Lottery, One Stop, and Tesco. Not always winning has taught me to challenge my perceptions of what makes a good application and do better next time.”

Achievements and impact

Carl has achieved a lot in the short 2-year history of his new organisation. They have lots of people involved as members.

“The achievement I am most proud of is the impact Challenging Perceptions is able to have in others’ lives, in organisations, and our community. I know this makes a difference in my life”

He can see the impact Challenging Perceptions has had on the people it has touched.

“People with mental health have found a way to live and go ahead into education, training or employment”

The future

Carl and Challenging Perceptions are developing to offer therapy to different groups of people.

“We’re just about to extend or befriending support and offer different therapies which will support people to achieve greater wellbeing and a better quality of life. I’m excited about that, and optimistic that the more our service supports young people the better able they will be to challenge perceptions and change perceptions of mental health.”



GRAHAM AND BIG HEALTH AND FITNESS

Graham

Graham was once one of the heaviest men in the UK, weighing 52 stone. After battling obesity and mental health difficulties, he decided to have an operation in 2012. He went on to lose 35 stone and became a specialist personal trainer.

Graham and BIG

Graham decided to start a health and fitness club to help people like him who felt excluded from mainstream support and lacked the physical and emotional confidence to go to the gym.

“There was nothing out there like this when I needed help. I’d try to go to gyms but thought everyone was looking at me. I worked with personal trainers, but some just didn’t get it or understand how to work with someone in my situation.”

BIG Health and Fitness was founded in March 2016 by Graham. He runs the business with Jude, a long-standing friend and former client, who lost 4.5 stone with diet and exercise. BIG Health and Fitness provide personal training, group exercise classes, as well as training and motivational speaking, courses and workshops to obese people and people with physical and/or learning difficulties. They are based in a fitness club in Luton, Bedfordshire.

What helped?

Graham had a personal drive to provide a service that was missing when he was on his weight loss journey. He and his colleagues had personal experience that allowed them to provide empathetic support to their clients.

“We wanted to provide support that empathised with people’s situation, put them at ease and delivered results”

Graham has a personal story that helps inspire people, is used as an effective marketing tool and provides a role model.

“My story helps get us heard and helps promote our service ...Graham is a role model. They respect what he’s achieved and look up to him. He can inspire people and because he’d been through it, he knows how to empathise and put people at ease”

Bringing on board Jude, a former client and old friend as a business partner, provided Graham with additional help and support.

“It really helped Jude coming on board as my business partner. It was difficult doing it on my own and Jude and I complement each other”

A local gym owner provided Graham and BIG with access to the gym and office space.

“The manager of the gym has been really supportive. He saw the opportunity and has given us space to work from”

Increasing recognition from, and relationships with, local community organisations and public bodies about their service have helped Graham and Jude to make BIG a success.

“We’ve built good relationships with local organisations, like the Council, CCG and Disability Resource Centre. We’ve been recognised for our good work. It is starting to open doors”

Challenges

Starting a business without experience has been a challenge and one made harder by a lack of local business support or mentoring that understood the sector in which BIG is operating.

“Neither of us have run a business or community organisation before or knew much about the health and social care world, and there isn’t much help out there.”

Gaining access to start-up and grant funding along with a steady and sustainable trading income has been an ongoing challenge for the BIG team. Many of BIG’s potential customers have ongoing health and/or care needs and there is potential for this to bring an income stream to the BIG business model. Graham, Jude and BIG have struggled to really understand and engage with public sector health and social care organisations.

“We have paying clients, but some of our clients need funding and we need funding to deliver services. It’s a lot of work to get the funding we need. We don’t need a lot to run the business and we always said it is people before profit. But it’s been difficult...”

Starting and running a business whilst living with personal health difficulties has also been a challenge.

“It’s difficult enough setting up a business, let alone dealing with your own health issues at the same time”

Achievements and impact

Setting up the business has been a real achievement for Graham and Jude. Since they started, they have supported over 200 people and have now trained 4 personal trainers to provide similar support.

In 2017 BIG gained the Dunstable and Houghton Regis Business and Community Awards; was MP's Community Business of the Year and was awarded highly commended Business of the Year in the Luton and Bedfordshire Community Awards. In addition, BIG Health and Fitness have several stories where they have helped people to change their lives by losing weight, getting fitter and increasing their confidence.

“We received this card from one of our clients. She'd been too obese to conceive. We helped her lose weight and she got pregnant. That's why we do it. For stories like that.”

The future

BIG Health and Fitness are ambitious. They want to help more and more people, both locally and nationally.

“It is about taking baby steps at first. We want to help more and more people. We're starting to get more interest and we're optimistic for the future. The business is sustainable, so it is now about growing it locally and nationally”



ASHLEY AND BOW WOW BICCIES

Ashley

Ashley is a young woman who lives at home with her Mum in Ayrshire, Scotland. She likes music, enjoys cooking, and swimming and loves spending time with her dog. After leaving school Ashley studied at College. Her time at College was reduced and Ashley and her family were considering how she might spend her time.

“Ashley’s college days had been reduced, so she was looking for something else to do with her time” - Ashley’s Mum Maureen

Ashley and Bow Wow Biccies

Ashley connected with a local project called Enterprising Minds run by the charity Hansel. The project was led by Alyson Miller who worked with local disabled people to help them explore their talents and passions and use them to set up their own enterprise or group.

“We found out about the Enterprising Minds project and had a meeting with Alyson Miller. We chatted about what interests Ashley has, and as Ashley made her own dog biscuits, the conversation focused on this. Ashley enjoys baking, and especially making biscuits for her dog.”

Together Alyson, Ashley and Ashley’s Mum Maureen decided that Ashley might like to set up her own enterprise, baking and selling dog biscuits. Alyson helped Ashley think through the practical aspects including the legal rules on food for animals; recipes for the biscuits; production methods; packaging; marketing; pricing and sales.

“So, they talked about her recipe, and how it was organic, and as natural as possible....We had to be careful what we put in them because our dogs have sensitive tummies. We had to see how long they’d last, and so get a use-by date.”

Ashley and Alyson talked about a name for her new enterprise and Ashley had lots of ideas from which one emerged as the best.

“Ashley came up with the name Bow Wow Biccies and it just snowballed from there. We had to have labels printed, they had to be trademarked, we had to learn how to invoice, and keep accounts, and barcodes needed to be added. It was quite involved and was really good to do”

Ashley and Alyson approached local pet shops and businesses with a connection to dogs and began to market the biscuits.

“Before long, a pet store got interested and she was selling them there. Ashley visited a restaurant in town that was doing a charity event where they gave Ashley’s biscuits to dogs. It kept us really busy, especially all the pots we had to wash!”

Ashley gained some income from selling the biscuits and she used this to cover her costs.

“Whenever she sold some, the money went into buying ingredients for the next batch.”

As interest in her biscuits grew Ashley decided not to develop her enterprise too much.

“Some of these businesses were huge, and they were talking about us sending crates of dog biscuits. But we told them we were just doing it from our kitchen! We thought about making it bigger, but Ashley just wanted to keep things small.”

What helped?

Ashley got a lot of help and support from her Mum, support workers and other people.

“We used a rolling pin!”

Ashley and her team got a lot of help from Alyson and the Enterprising Minds project at Hansel.

“We got lots of practical advice and information, particularly from Alyson at Hansel. She really helped us to deal with the insurance side of things. She helped us to figure out how to do the labelling, to choose all the colours, sizes, prices. She helped us get finances to fund the first batch, which were paid for by Hansel. Alyson kept in regular contact with us, and whenever we were stuck with anything, we were always able to contact her.”

Challenges

Ashley needs a lot of support to live her life. This means it can be challenging for her Mum and other carers to help her run her enterprise.

“It was more about helping me to support Ashley, as this was extra, on top of the more practical support. It was hard at times, depending on how Ashley was so that was a challenge.”

The Enterprising Minds project came to an end and this has had an impact on Ashley and her enterprise.

“We know how to do it all now, it is just having that extra pair of hands really. Ashley needs more support with this. I can help, but I just can’t do it in the way that Alyson did it.”

Achievements and impact

Ashley has gained a great deal from her involvement with Bow Wow Biccies. She is proud of what she has achieved, and her sense of purpose and self-esteem has increased considerably.

“[Before Bow Wow Biccies I was] just going to college and cooking. It made me feel good.

She was proud to be selling them at the pet shop, and the restaurant, and thinking about all the dogs who would be enjoying her biscuits. It gave her a discussion opener. People would come up to her and speak to her and ask her about it. She really enjoyed people speaking to her about it and coming up to her and asking if she would make biscuits for their dogs. It gave Ashley a real sense of meaning and purpose.

I could see a really positive change in Ashley, as she felt more useful and productive. It was also a big help for me. Everybody should be given the chance to pursue the things that matter to them, as it really does make a difference.”

Ashley also gained a positive reputation in the local area.

“It was quite bizarre how many people knew about it, and how many people were connected through it. She had a wee bit of fame because of it!”

The future

In recent times things have been on hold but Ashley would like to start making and selling dog biscuits again.

“We have been talking about doing the dog biscuits again, because summer holidays are coming up, and there will be lots of dog walking events down at the beach”

JULIE, PEER SUPPORT AND CHARD WATCH PROJECT

Julie

Julie lives in Chard in Somerset and has a history of mental illness. Julie had positive experiences of mental health services but didn't always feel they offered what she needed.

"I had some excellent services and support from the formal system. I didn't feel failed by them, but I didn't feel all of me was heard."

Whilst using mental health services she learned about intentional peer support and experienced the positive impact it can have on people's lives.

"I was a patient in the mental health system...I was unemployed and felt that there was no way out. At the local day centre someone handed me a poster around intentional peer support and funding for 35 people to learn about it. I saw how peer support can make a difference."

Julie and Chard Watch Project

Julie decided to set up an intentional peer support group in her hometown. This ran for many years, on a small scale – growing and developing organically as people got involved.

"Steadily we grew and gained support from local voluntary, community and housing support organisations, who gave us time, reassurance and small amounts of funding."

At the same time many of the traditional day services were closing meaning there were more people who were isolated. The group turned into the CHARD Watch Project which has now evolved to also support emerging peer support groups in other areas.

"Now we are able to facilitate other areas to set up their own peer support groups. We train people to find their own way in their own potential. Enabling people to be enablers of themselves. Anything that shows people that they can do something... is worthwhile."

What helped?

Julie gained a great deal of support from her peers.

“This meant that I was not alone. Being with people who shared their experience and their passion, I felt connected and not alone with my mental health. This gave me power and unlocked me in a group setting.”

A number of organisations, such as the Community Foundation gave Julie and her peers support at the start of their journey.

“The support they offered gave reassurance, confidence and small pots of funding. They supported us but didn’t put too many barriers in our way. They let us have our own personality.”

Feeling validated internally and externally was very important to Julie and boosted her confidence and motivation.

“Awards and certificates all meant a lot to the project in the early days.”

Challenges

Julie feels her biggest challenge is taking time to stop and listen - allowing the group to show the way whilst also creating an environment that challenges and encourages people.

“Letting it happen can be a challenge. How to keep people at the heart of decision making and not making them dependent. The way we speak and the language that we use is so important.”

Another challenge is working with partner organisations who have a traditional or structured approach to projects.

Achievements and impact

Julie has a real sense of achievement in simply helping people.

“Anybody who comes in and finds someone to speak to is an achievement. We have 35 people who attend the Thursday groups regularly. Everyone’s story is amazing. We have over 100 members but always have new people. To see people coming out of themselves, making a friend or talking for the first time. Playing pool, building their communications...”

She is proud of the role she and Watch have played in facilitating peer support groups in other parts of Somerset.

“I am passionate about peer support because it is not time or outcome driven. It is about being a friend first, someone who is there. It is not about fixing people.”

The future

Julie feels it is important to consolidate the work of the Watch project in the near future.

“At the moment we are fine tuning our project and the challenges we are facing. Recently we have had funding from the National Lottery Community Fund which included an organisational strength review and this will help us focus on our strengths and weaknesses. So easy at times to lose track of our original vision when fundraising and can lose your way.”

She wants to develop the work to be able to help more people in more and different places.

“We want to make sure for ourselves that we carry on developing peer support and creating a warm, safe and welcoming project to help isolated people living in the rural areas connect with others.”

ROB AND TACT

Rob

Rob grew up with hard working parents but as a teenager he got involved with drugs and as he grew older, he got in trouble with the law. His family life was troubled and chaotic, and he also struggled with mental illness.

“I was 14 when I got involved with drugs, I was selling heroin and using it before school just to feel normal. By 21 I’d been in 4 young offenders places and as an adult it was prison. I had children and they were put on a care order. So, I had to go to a contact centre with social workers to see my kids. I’ve been through mental health services too...been sectioned...”

At 36 he found himself in prison once again. On release he decided to make a change.

“I got out of there and sat in front of the mirror and thought ‘I don’t like you and I don’t like the way you’re looked at by other people’ and I just stopped. I stopped using. I managed to get a studio flat. I started looking at courses and went on health champion courses.”

He thought about the future and realised it would be hard to get a job. He began to wonder whether he could create something that might help him and others.

“I’ve got a massive criminal record, I’m an ex-drug user. I thought ‘what am I gonna do?’ It was like I was standing in an open field, not knowing what direction to go in. It was about choosing a point on the landscape and walking towards it. Me and another lad...came up with an idea of a smart recovery group. For weeks no one turned up. I just sat there on my own, but I’m an addict so I just kept going! After about 12 weeks people started to dribble in”

Rob linked to a service user group run by the local drug team and over time the group became independent. This developed into a small support and then a vision of a new organisation, one focused on people and recovery.

“I got offered a free office at the local drug team and I set up there. It was quite weird...about 2 years before I was barred from the building. I think that was the platform that I needed. I moved and I started to give talks about what I was doing and what the vision was”

Rob and TACT

Rob was told about a capital grant opportunity. He put in a bid, was successful and used the grant to purchase a building, which would become the base of his new organisation, a CIC called Telford After Care Team (TACT).

“In 7 years, it’s gone from me and a Nike bag to owning the building and having four contracts with the NHS and Public Health.”

The organisation has developed and grown over the years and they now offer a multitude of activities and opportunities.

“We’ve got a print company, a landscape gardening company, a café, a training company, and a female housing project. We get up to 90 to 100 people a day through the doorway accessing courses and groups. Everything we’ve done has been through people’s voices”

Everything they do links to recovery and is led by people with lived experience.

“We give opportunities. Above our door is a sign with ‘recovery through discovery’ written on it and that’s what we do in a nutshell. We discover people’s talents are and we grow them”

All organisational development is organic, creative and led by people and their experiences.

“I speak to the Police and Crime Commissioner and get a pot of money. Then I go and see someone from the Council and get them to match fund that pot of money. We buy a van, equipment, uniforms or whatever. Projects like that don’t make any money but they cover themselves and they give people opportunities”

What helped?

Rob was supported at the start by the local authority and primary care trust (PCT).

“I had some good commissioners at the time who believed in it. I got the first lot of funding”

Rob had a drugs worker who gave him clear advice and a lot of support.

“I had an amazing drug worker who was very supportive. Now he works for me so he’s been a massive sort of mentor and a big part of my life... so I’m not letting him go too far!”

He is clear his success and the success of TACT is down to teamwork and strong networking.

“It’s about keeping the right people around you. It’s all about positivity. It’s going out and networking, networking, networking and selling your story. I’m a salesman, that’s what I do, I sell recovery to people and not just people who are in addiction or around mental health”

Challenges

Funding and secure income has been an ongoing challenge for Rob from the start of the early groups to the emergence and development of TACT.

“As you grow obviously, you’re gonna need more money to run it. It’s always a battle to keep open, funding right across the country is crippling people.”

Some of the finances on offer have come with strings attached

“We’ve done this stuff where money’s been offered but with the requirement that people from the Council manage it. We’ve said ‘no’ and caused upset. I’ve always stuck to the vision”

Achievements and impact

A huge achievement for Rob is gaining custody of his 2 sons and becoming a good parent after a challenging history.

“Getting custody of my kids and bringing them up. My eldest, he remembers me at my worst...They’ve been part of that recovery journey. My lad still comes to my recovery group and he’s 15. They’re the level-headedest kids because they’ve seen it, and seen people who have come through that madness of addiction”

Rob and TACT have won several national and local awards and he is regularly asked to share his story and successes at events.

“Talking at conferences, being asked to go along and talk about my stories is always rewarding...where if I reach one person in that crowd who will go away and try in their area.”

TACT has given Rob a real purpose in life and it has also given him an opportunity to work.

“It’s given me a purpose in life I suppose and deciding to set it up as a CIC and take a wage. I’m employed by the company I set up.”

Seeing the impact on other people has a huge impact on Rob and others at TACT.

“I come to work and work with the people who were me and we support each other. My new drug is to sit in a recovery group and hear how well people are doing. What we’ve done is made recovery visible. We’ve put choice in the hands of the people who are getting clean, hundreds and hundreds of people have come through and done well. Massive massive impact.”

The future

In the future Rob and TACT want to help more people in as many ways as possible.

“If I get drug workers and probation officers ringing and saying ‘I wouldn’t work with him’ that means I’m digging my heels in with this lad and I’m going to mentor. It’s the ones that have been written off that are the ones that will do the best.”

Rob aims to make TACT self-sustaining in the medium term.

“The model is to be self-sustaining, that’s what our business plan says. We won’t need funding in 5 years. The small businesses we set up which give people the opportunity will then go towards running the organisation. So, any profits made will go back into the middle.”

TOGETHER ALL ARE ABLE

Together All Are Able (TAAA)

Together All Are Able is a small Community Interest Company (CIC) organisation on the Wirral run by and for disabled people. Vicky, Jenny and Kieran are 3 of the 5 Directors of the company together with their colleagues Lynn and David.

“We are the bosses of this organisation. We don’t answer to the council or anyone else”

TAAA is a membership organisation for disabled people and their families. The organisation has a strong self-advocacy role locally, regionally and nationally and offers support and activities for its members.

The journey to TAAA

Vicky, Jenny and Kieran have strong personal experience as disabled people. Kieran and Vicky both attended special schools and experienced the low expectations people had of them.

“I attended a local special school and quickly realised the work I was being given was nowhere near the same level as the people I knew who were at mainstream school. There was zero ambition and zero aspiration for people”

From school Kieran went to residential college where he saw some of his peers going off to University. This made him realise what was possible and sparked a fire in him to improve his own life and the lives of other people. Vicky and Jenny graduated from the development programme ‘Partners in Policymaking’ which helped them learn about the history of disabled people.

“It was quite depressing. But it put the fire our bellies to want to make a difference to disabled people, particularly those who use services”

Jenny and Vicky were offered an opportunity by the local Council to develop self-advocacy on the Wirral. After some early challenges the pair, together with colleague David set up Together All Are Able in 2011, where Kieran joined them in 2013.

What helped?

Every member of the team has strong personal qualities that have enabled them to start and sustain TAAA.

“Without that drive I don’t know if we’d be here today”

In the early days the team were supported by the Council and Wirral Connect a local community and third sector development organisation. Wirral Connect helped the team think through the legal issues of setting up a CIC.

TAAA are based within a small sports centre which is run by a local charity. The charity offers TAAA use of an office and other facilities at a very low rent. Every member of the team gives time and goodwill for free and this has been a strong factor in the sustainability of the organisation.

Social media has played a strong part in raising the profile of TAAA locally, regionally and nationally; giving the Directors an opportunity to air their views and experiences and connecting them to other people and organisations of a like mind.

“Social media has been a godsend. It has given TAAA a verbal platform. It has really raised our profile”

Challenges

The team gained early support from the Council, but this was withdrawn, and they lost the venue where they had been based. The team faced uncertainty as to the future of their emerging organisation.

The team have been challenged by attitudes towards disabled people and self-advocacy.

“They say that people can’t speak up for themselves”

Achievements and impact

The team feel proud that their organisation is truly led by disabled people and that is surviving over time.

“We are still here. That is a real achievement”

TAAA has a positive relationship with the council and CCG and feel their voice is heard and has influence. The Directors also play a strong role on the national stage. Jenny recently won the Derek Russell trophy for outstanding leadership and Vicky was nominated as a leader on Dimensions Leaders List. Setting up and running TAAA has had a big personal impact on Jenny, Vicky and Kieran.

“It has given me a lot of confidence...but not much free time!”

It has put self-advocacy on the map locally and opened doors to much wider opportunities to engage and influence.

“Our voice, the disabled voice, is heard locally, regionally and nationally”

The future

Jenny, Vicky and Kieran would like to see TAAA grow with more members and offering more services and activities. The fact that they are independent is seen as key to their continued success.

“Self-advocacy groups up and down the country are failing as their funding is cut. We don’t get funding so don’t have to worry about that”

The team would like to develop their income streams and eventually be properly paid for the work that they do.



SAPPHIRE, PHOTOGRAPHER AND CARD PRODUCER

Sapphire

Sapphire lives in Ayrshire in Scotland, she is a keen photographer who enjoys taking pictures of local scenes.

“I used to see pictures in magazines, and think ‘ooh, I wish I could do that!’”

Sapphire is a disabled person who in the past was shy and struggled to appreciate her skills and talents.

“I felt shy because people don’t realise that people with disabilities can do things. So, we hide our talents because we’re scared of people judging us”

Sapphire and cards

Sapphire connected with a local project run by charity Hansel called Enterprising Minds. The project was led by Alyson Miller who worked with local disabled people to help them explore their talents and passions and use them to set up their own enterprise or group.

“I was introduced to Alyson by my OT who said that she’d heard of Enterprising Minds, and that it might be a good idea for me. Alyson came to visit me and looked at my pictures on my phone. At first, I didn’t want to show them to anybody. But I slowly agreed to do it. Alyson really liked my pictures and asked me if I’d ‘like to show people how good you are?’”

Together they came up with the idea of turning Sapphire’s photos into greetings cards. Alyson helped Sapphire think about all the practical aspects of doing this, to source materials, make and package the cards, work out pricing and find potential customers.

“Alyson helped me to turn my photos into cards, and then she came with me to talk to the people who run the shop, who agreed to sell my cards. My cards started to sell like hot cakes. One day we went in, and they’d all sold out. People were coming in and saying, ooh, those pictures are unusual, I like them.”

What helped?

Alyson and Hansel supported Sapphire to appreciate her skills and think how she might be able to use them.

“It was good to be given a challenge. Most people with disabilities are hiding”

She also gained support from family and professionals and local businesses who helped her to sell her cards.

Challenges

Initially Sapphire was uncertain about her talent and lacked the confidence to use it well. She was also challenged by some of the practical aspects of making and selling her cards.

“Cutting the pictures to the right size for the cards. I found this really difficult”

Sapphire had a period of ill health and this has had an impact on her ability to make and sell her cards.

“Being in hospital because I had been ill. I really wanted to do the cards again, but I just needed to get myself better first.”

The Enterprising Minds project came to an end and this has had an impact on Sapphire and her enterprise.

“It feels like it’s all been paused. Things are go, stop, go, stop, and we need them to keep going.”

Achievements and impact

Sapphire has gained personal confidence from making and selling her cards.

“It’s made a big difference. It has helped me to be more confident, because I used to be shy”

Sapphire has also gained some income from her enterprise which helped her buy materials for future card production. It also had a huge impact on her self-esteem.

“There was money in the jar and I was speechless. It was the first time I had ever earned money in my life, and I was totally shocked. I was really happy to be making money back from this. It also helped me to buy the things I needed to carry on.”

The future

Sapphire has some great ideas as how she might develop her enterprise including putting pictures into different formats such as mugs and on canvas.

“I was thinking maybe sometime in the future to see if we could put the pictures on canvas, and maybe put them in a cafe somewhere. I would also like to put my pictures onto mugs.”

She is clear that people in her position need help and support to shine and that is not always available.

“We need more projects like Enterprising Minds. At one time, I was like, I don’t want to show you, but then someone said, come on, you’ve got talent, and in my mind, I would say no, I’m going to get judged. We need more encouragement, because people are always closing doors on us. People are always telling us what we can’t do. Sometimes we need someone to see what we can do. Someone to give us a wee push.”



ANNA AND THE COALITION FOR COLLABORATIVE CARE

Anna

Anna trained as a Dr for 6 years before her new career was cut short after 6 months when her health deteriorated, and she was forced to leave her job. During some very hard times Anna was forced to take stock of her life.

Anna and the Coalition for Collaborative Care

Anna became aware that the Coalition for Collaborative Care (C4CC) was seeking people with lived experience of long-term health conditions to join their newly formed Coproduction Group. C4CC are a major influencer at a strategic level, working in partnership with NHS England and others to make health care and related supports more personalised.

Anna saw the opportunity to join the Coalition at the same time as she was coming to terms with her health condition and the impact it would have on her anticipated career pathway. She had a professional knowledge of the NHS, a need to use her skills and knowledge and a strong personal drive to improve things.

“I wanted to help people. I also wanted to feel that I was still useful. The opportunity came at just the right time. I didn’t know what coproduction was but thought - I’ve got lived experience”

Anna joined the Coalition and began to learn about personalised approaches to health and social care. She realised that her experience was a long way from personalised.

“The system doesn’t look at the whole of me. At one point I had 7 consultants and none of them spoke to each other”

Recently Anna became the Co-chair of the Coalition.

What helped?

Anna sees herself as determined with a need to be active, to contribute and find solutions to problems. These characteristics originally drove her to become a Dr and continue to drive her work with the Coalition. She also has skills which enable her to deliver her role well including professional and personal knowledge of health conditions and strong problem-solving skills.

Anna is paid a participation fee for the time that she gives to the Coalition, she gets the support that she needs to contribute, and the cost of her expenses are covered.

Through her work with the Coalition Anna has met people with experience who have shared their knowledge. Anna sees their support as key to the success with the Coalition.

“I have met some amazing people, many of whom have given me great advice”

Challenges

Getting around using public transport is a real challenge, as is finding accessible accommodation when travelling for meetings. Accessibility can also be an issue at venues with organisers who have invited disabled speakers, sometimes unaware of the physical barriers presented by their chosen venue

“It is not easy being disabled and using public transport. I went to an event where the disabled toilets were upstairs. The only lift was too small for my chair. Other disabled speakers and I were forced to go over the road to Starbucks to use their toilet”

Anna needs help to travel and carry out her role within the Coalition but does not get any extra hours built into her package of social care support. Systems are complicated and don't link up well to enable Anna to do what she does.

“Through the Coalition I am trying to make a positive difference to health and social care on a national level. On a personal, local level they are the ones that make it difficult!”

Achievements and impact

The Coalition has been influential in the development of the Universal Personalised Care Model and its inclusion in the NHSE long term plan. It has found opportunities to influence at the highest level and Anna has played a key part in this. When the Coalition first started the level of work that was coproduced was limited. More recently this is much stronger and the voice of people with lived experience is key in all areas.

Contributing to the leadership of the Coalition has had a strong impact on Anna personally.

“I have a sense of purpose. I have rebuilt my confidence and skills. It offers me a good challenge and I would miss it if I wasn’t involved.”

The future

In the future Anna hopes to be in the same or a similar area of work

“Chipping away at the bigger picture and trying to bring change in some way”

She now feels knowledgeable and skilled in work around health and social care and coproduction.

“I have learned about how this all works and am determined to help it move in the right direction”

She is mindful that NHSE and other health organisations have a strong and evolving personalisation strategy but understands that they don’t always make the link with historical work on personalised approaches from a social care perspective.

“I don’t want to see health bring in personalisation in a tokenistic way that is not doing things to help people live their lives their way’ I want to see real culture change and power sharing. I want change to be coproduced and able to make a positive difference to people’s lives”



BRENDA AND PAIN MANAGEMENT PEER SUPPORT

Brenda

Brenda is an 83-year-old retired sales manager. Shortly after retirement Brenda had 3 car accidents, each no fault of her own, which left her semi-disabled with a chronic condition. As a result, she lives with constant pain. Once her treatment was complete Doctors invited Brenda to join a group to talk about pain. Brenda found that talking about pain really helped her. The physiotherapist at the group suggested Brenda and another person from the group should set up their own group.

Brenda and pain management peer support

Brenda founded two pain management peer support groups aimed at people who live with chronic pain: 'Friends through Pain' in Fareham and 'Partners through Pain' in Gosport.

“The groups are purely social, not medical. They have a criteria of chronic pain for joining”

The original Fareham group started with 3 members and used to meet in Brenda's house. When numbers rose, they found new premises in a local hall. A GP in Gosport heard about the Fareham group and contacted Brenda to ask if she would set up a similar group in Gosport.

Each member pays an annual subscription to cover the costs of the hall and there is a cap of 30 people in each group to make sure it's manageable. The groups meet once a month and often invite speakers. Once a month each group will also go out for lunch or a coffee. During the warm months Brenda also arranges group outings. The Gosport group have been to London to watch a show and stay over in a hotel. Members of the groups also do things for other members outside the meetings.

“There is no magic cure for chronic pain. We are self-supporting of our illnesses. We all go through good times and bad. We've got to help ourselves as there's no money to help us [through the NHS/government]”

Brenda is also part of a local group who reviews NHS research papers around older and disabled people and provides feedback.

What helped?

Brenda and the groups are supported, but not funded, by the Rheumatology Department at the Queen Alexander Hospital in Portsmouth. The groups often have speakers from the health sector including Colin, a matron from the Rheumatology Department. Colin sometimes invites Brenda to health roadshows which allows Brenda to raise awareness of the peer support groups and attract new members. Brenda and the groups also get support from a pain management professor at Southampton Hospital and from local GPs.

Challenges

One of the greatest challenges for Brenda is getting people to join the groups. She attends seminars and lectures and speaks on the radio. Often people are enthusiastic at the venues but don't end up joining the group, even when Brenda has had a follow up call with them. Brenda has also been on Radio Solent to promote the groups.

It is very, very difficult to recruit. They don't realise what they can get out of [joining]"

When planning trips Brenda faces the challenge of making the arrangements, researching every part of the journey to make sure it's disabled friendly.

Raising money to cover the cost of running the groups can also be a challenge. Brenda tries to keep member contributions to a minimum so fundraises for the group. The groups have a raffle and hold cake sales. Brenda also applies for grants.

"[Applying for grants] is very tough work"

Achievements and impact

The fundraising and events have been a success and there has been increased awareness of the groups locally.

Brenda received a nomination to go to Buckingham Palace for the work she's done which gave her a 'tremendous lift'. The groups have a huge impact on their members.

"Once people get one illness, they often get two, three and four. If you have chronic pain you are likely to be isolated and this can lead to depression. Families and friends don't see a bandage so often think the person is better but everyone in the group understands and what it's like. One member told me we had given her a reason to live"

And personally, Brenda also enjoys running the groups and has support for herself.

"It has made my retirement more interesting!"

The future

Brenda has relinquished her duty as chair and as she gets older, she is thinking about other people picking things up. She has recently asked one of the members to sit with her when she applies for funding, so they know how to do it.

PEOPLE DOING IT FOR THEMSELVES

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