

THE BEST THINGS IN LIFE

The impact of Grapevine's work on people with learning disabilities and their families



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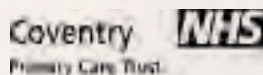


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‘THE BEST THINGS IN LIFE ARE FREE’*

This report starts with a line from a song and each section starts with a popular saying. Gathering information about our 2011 work under these headings seemed right because a lot of good sense is captured in the sayings themselves.

Being connected to other people, having friends and people you can count on, playing a useful role in life, being a citizen – these are the things that make life worthwhile and, for most people, they are free.

But people who have a learning disability often need some support to get a life connected to others – people who will help them to develop the strength and skills to cope with life’s ups and downs. And that help is available in communities if we know how to find it. This is Grapevine’s speciality. Building on the strengths of individuals and the positive things in communities is the heart of our approach.

Most people, though, only get support when they have a crisis. It’s not a good way of spending public money. Of course, it’s important to help people in trouble. But far fewer would suffer expensive crises if they’d had the right sort of help early on to deal with the life ahead.

Imagine a few years of a strength-based approach spread across all services. There would be tens, probably hundreds, of thousands more people standing on their own feet and making a contribution to society: volunteering, working, supporting others. Preventing problems rather than coping with the consequences – it’s common sense.



The Beatles didn’t say this first. It was Buddy De Sylva, an American songwriter.

PREVENTION IS BETTER THAN CURE

‘A stitch in time’, ‘be prepared’: we all know sayings about prevention being better than cure. It’s common sense.

Government knows this, too. It urges local authorities to prevent need. But those authorities have limited cash and they often set the threshold for care so high that you have to be in crisis before you get help.

What if you could get help from those around you before things went wrong? A recent report, **Sinking and Swimming** by the Young Foundation, says transition ‘...could be an area for long-term savings... as well as much greater human wellbeing’ – if only everyone had someone they could turn to.

Grapevine, too, believes the stitch in time is made by connecting with others – people who can help you to get over problems, become stronger, more resilient and not feel you’re stuck on your own.



LEAH AND MOLLY

Leah's story will ring bells for many teenagers and their family.

Leah is 16 and knows it. She's ready to be independent. She's sassy, fun, bubbly and determined. She also has Down's Syndrome. Until now, unless she was at school or its youth club, she would spend her time with her two younger sisters, her mum, her grandparents and the dog. It's hard to grow up if you're not around other teenagers.

Leah wanted to be out on her own – to cross the road to see her Grandad (her hero) or go to the shops by herself. Her mum realised she had to let go a bit. That wasn't easy, though. She was worried Leah would run off or get hurt. She needed reassurance that Leah could be more independent and be safe.

Through Grapevine, Leah met another teenager, Molly, her buddy. Molly grew up in the same area and knows the local community. They've started going to Grapevine's Get In group together. They go to the pub, play pool, go into town for a meal.

Their friendship is growing. It's not all plain sailing. What teenage life is? There's the odd hiccup – Leah is sometimes reluctant to leave the pub! But Leah's mum sees the value in the friendship. She says 'With Molly, Leah can do teenage things without always having her mum there.'

IMPACT

In 2011, Grapevine helped 169 people with a learning disability to develop the strengths and relationships they need to avoid crisis and dependency.

43 of them were young people under 25. When we started working with them, none was involved in their community and few had friends or informal sources of support around them.

As a result of our help, people made new friends and relationships, had more control over their lives and gained a stronger feeling of well-being.

TWO HEADS ARE BETTER THAN ONE

When we face a difficult problem, what do most of us do? We 'put our heads together'. Usually, ideas come up that we may not have thought of on our own.

Most of us put our heads together with family, friends and neighbours. But, if you're cut off from other people, new possibilities are less likely. This is the situation for many people with learning disabilities. They might spend all their time at home or be isolated from the community because they live in a special 'service'.

People become stronger, are safer and have better prospects when they have relationships with others. That's why one of Grapevine's main activities is 'connecting people'.



CHLOE AND JEN

No friends, lonely, isolated: not the life anyone wants. But this was Chloe's life.

Chloe was shy. She seldom looked up and gave little away about how she was feeling. A fulfilling life has real friendships and relationships. How could Chloe get these? The answer started to form as Natalie, a Grapevine Community Connections worker was on a 5.30 a.m. run. She described her job to Jennifer, her running partner. Jennifer was interested.

A possible match took shape in Natalie's mind: Jennifer had just opened a hairdressing salon, Chloe loved all things feminine. So, bearing coffee and muffins, Chloe and Natalie arrived with the plan of 'hanging out and seeing what happened'. It was a little uneasy at first. Chloe was reluctant to get out of the car; Jennifer was uncertain about how to communicate with someone who doesn't use words.

But now Chloe springs out of the car leaving Natalie to bring the coffees. Chloe likes the atmosphere of a grown-up women's place. One of the customers talked about Chloe having a lesson at her daughter's riding school.

Her mum says when Chloe's off to the salon 'the biggest smile comes on her face'. Jen says 'We have more in common than I could have imagined. Long may our friendship continue.'

IMPACT

In the last year, 68 people got the support they needed to meet new people and build a social network.

Through meeting new friends, people got involved in all kinds of activities, for example: going to record stores and gigs in Birmingham and Leicester; dj'ing alongside regulars at a community radio station; going to zumba classes (without worrying about how to get there); joining weightwatchers and yoga groups.

A PROBLEM SHARED IS A PROBLEM HALVED

A farmer wanted his sons to pay attention to their enemies rather than squabble with each other. He asked one son to break a twig. The son did it easily. He gave a bunch of twigs to the other son who couldn't break them. 'Unity is strength', said the farmer.

Grapevine has learned that communities are powerful when people act together. They can solve problems that professionals can't. That's why Grapevine helps disabled people to make the most of their skills and offer these in the community.

We support people to work with other community members to solve local problems.



CHRIS AND MARGARET

Chris, Margaret and their daughter live on a tough estate. It's especially difficult for them because anti-social neighbours spotted their vulnerability. Pretending to be friends, people would come in, take over the flat and use their phone.

This went on for years. Then things got even worse. Margaret says 'We were hounded by some people. They swore and shouted at us, put rubbish through our letterbox. They would knock our door at night with masks on. They even stole our daughter's birthday balloons and banners. It was horrible. We phoned the police but they didn't take us seriously.'

The turning point came when an older neighbour reported the harassment to the police. She accurately recorded the times and nature of incidents. Chris and Margaret felt reassured that a neighbour spoke up for them.

Meantime, Grapevine helped the couple talk to the housing agent, which tackled the family causing the trouble. Grapevine also helped Chris and Margaret understand their own tenant responsibilities because neighbours had complained about them being noisy.

Things are looking up. Through Grapevine, Chris and Margaret have met another couple who invited them for a BBQ and movie nights. The two men enjoy vegetable gardening. In fact, there is a growing community of gardeners that help each other out – including the older neighbour who called the police.

IMPACT

During 2011, Grapevine helped 109 people with learning disabilities to get the information, representation and support they needed to deal with a crisis – almost twice as many people as in 2010 (58).

The main problems faced by the people we helped were:

- legal proceedings, particularly against parents with a learning disability
- family conflict, financial and other abuse
- managing change, for example moving home and getting better support.

Grapevine's citizen advocates provided a network of long-term support to help people avoid crisis in the future. For example, a young single parent dad now has the friendship and support of an experienced, older father.

IT AIN'T WHAT YOU DO, IT'S THE WAY THAT YOU DO IT

The NHS is something to be grateful for – expert medical help for all. By and large, medical professionals know what they're doing. Knowing what to do, though, isn't always enough. How you do it makes the difference.

Knowing how to work with people, how to say things, how to listen – these can decide the outcome. A recent report, **Dignity in Care**, highlights how this is true for older people, who didn't get even the most basic standards of care. But the same is true for people with learning difficulties. That's why the work of Grapevine's H Team is so important.



THE H TEAM

‘Scary’, ‘lonely’, ‘not treated with respect’ – this is how some people with learning disabilities describe hospital. Following Mencap’s report, **Death by Indifference** (2007), 74 families contacted them saying unequal treatment had contributed to the death of their relative. Too often, diagnoses are flawed because staff mistake symptoms for aspects of learning disability – ‘it’s just the way they are’.

To its credit, the NHS in Coventry is working with Grapevine’s H Team to change things. The H Team – all people with learning disabilities – has trained hundreds of health care staff in working with people with learning disabilities. With the Coventry and Warwickshire Partnership Trust, the Team has also produced an interactive DVD that prepares people with learning disabilities for a visit to hospital.

Training sessions help staff to break down the myths and see everyone as an individual. They role play what it’s like to be on the receiving end – being ignored, professionals giving up on them.

Healthcare Assistants have been the main participants and they are seen as the most knowledgeable on the ward. They think all health professionals should get the training: ‘Put yourself in their shoes and you see the need to treat people with respect. Everyone should get training in this taboo area.’

The H Team works with medical students at Warwick University, too. So, at least some new doctors will avoid mistakes that have cost people with learning disabilities their lives.

IMPACT

Last year, the H Team trained 176 health staff including Health Care Assistants, GPs and GP practice staff and 123 student doctors and learning disability nurses.

This is what some of them said: ‘It really made me think about how we offer appointments for people with learning disabilities. I’ll go back and discuss with my surgery team’.

> Member of GP practice

‘A role play hit the nail on the head – short but powerful.’

> Health Care Assistant

The training ‘can only improve how we will be as doctors’.

> Medical student

‘I found all the training useful... the service users had been trained well to teach us to feel comfortable.’

> Student learning disability nurse

MAKE A HOUSE A HOME

Bricks and mortar make a house but they can't make a home – unless we mean a care home. For most people, 'home' means the haven we come back to, the place we can do what we want.

However, for many people with a learning disability and older people who need support, a home is somewhere they're put – a place where staff decide what happens.

Grapevine's Quality Checking team inspects homes on behalf of the Council and recommends changes that will put the residents more in control so they get the life they want.



QUALITY CHECKING

‘It seems like some older people in those places are disconnected – just waiting to die.’ Dave McCann, one of the people with learning disabilities on Grapevine’s Quality Checking team, doesn’t mince his words. His ability to get to the point has contributed to the impact that Quality Checking has made on services.

For years, Quality Checking has inspected homes where people with learning disabilities live. Since September, they’ve been inspecting services for older people, too. At first, staff around older people’s services were sceptical. But they soon saw the benefits of Dave’s eagle eye and the team’s constructive recommendations.

One service responded with a two-page list of ideas for improving people’s quality of life. Holidays with Saga, trips to the Coronation Street set, a new laundry service so Personal Assistants spend more time one-to-one and less time on laundry, voluntary work in charity shops, closer working with nutritionists – these are just a few of the plans.

Meantime, inspections of homes for people with learning disabilities continue. Quality Checking look out for how much people are involved in their community. Some good things are happening: for example, a woman in her 50’s, who used to be unknown to her neighbours, started a magazine swap in her close and has become something of a local celebrity. Quality Checking warn that there’s still a lot to do. Too many people lead isolated lives – especially older people.

IMPACT

In 2011, our Quality Checking team audited nine learning disability services and fourteen services for older people.

The target in 2012 is thirty-four audits. Our contract doesn’t include time for follow-up visits to see if services have acted on our recommendations. The story on the left, though, shows that some services take our recommendations very seriously.

Others have, for example: made individual plans in easily understandable formats; included service-users in interviews; supported people to help run the place they live or go in the day; made sure people have front-door keys; helped people to be involved in the local community; supported people to register as voters; reduced the number of official signs where people live.

ACTIONS SPEAK LOUDER THAN WORDS

Words are cheap. It's easy to talk a good game of football or, for that matter, a good support service for people with learning disabilities.

It's what we do that counts and, more importantly, what the people we support do. That's why self-advocacy – people speaking up and acting for themselves – is an acid test in our work. If we support people well, you will see them being assertive and taking action.

We have supported people to speak up and we think they've outgrown our support. So we're starting again, working with new groups, for example, people who are isolated or who may not use words to communicate. Can we do it again? Watch this space.



STARTING AGAIN

Grapevine has been 'doing self-advocacy' for years, helping people to speak up for themselves. Lately, though, we realised we had to change. Members of our Citywide group had become mature self-advocates – the experts we turn to for help.

So, we've gone out to talk to new people: younger and older, those living independently, those in services, people at college, people who need a lot of support. We wanted to start where they are – what's important to them? It's not straightforward. People often don't know what their issues are or have lived a life that is far from ordinary.

Money is a big problem. People we met in college groups didn't have even 20p on them. People living independently didn't know where their benefits came from. One person said 'Money comes from my mum's purse.'

Money is the tip of the iceberg. We're starting on mate-crime and also working with people to understand what are reasonable expectations in life – what kind of home they might have, what kind of lifestyle. Then there's making and keeping relationships, which is probably a lifetime's work for anyone.

Working in a self-advocacy way in these areas is challenging. It's exploratory, reflective. We can't assume anything. We're learning a lot and are feeding back useful – and sometimes startling – information to the City Council, the voluntary sector, Health Authority and elected members.

IMPACT

In 2011, the self-advocacy project helped 77 people, 55 of them on a regular basis, to get more choice and control over their lives and services.

At the beginning of the year, most said they were not able to make important decisions in their lives. By the end of the year, two thirds said they were enabled to take part in decisions as much as possible. The other 33% said they now 'determined their own life choices'.

EVERYONE A WINNER

You could argue what's more important in sport: winning or just taking part. But there's no doubt that being involved in sport is good for you – win or lose.

Sport is good for health in so many ways: heart, lungs – everything. It helps people shed the pounds if they're overweight. Just as important, it makes you feel better. Running, jumping, kicking, throwing, shouting: these activities produce endorphins in the body. You feel happier.

Grapevine sees sport as being more and more important. It's a good way for young people, especially men, to bond – make a relationship. And, as in all areas, prevention is better than cure. Ask a doctor how much treating diabetes or heart disease costs. Sport can be free.



KEVIN

Kevin thinks, talks and plays football. He started going to the Monday training sessions Grapevine runs with Coventry City's Sky Blues in The Community. Then he joined the Ability Counts team that plays at Villa Park.

Generally, life is good for Kevin. Through football he's met a lot of people and now has some close friends. Kevin's dad got involved too. He and Kevin pick up other team members for the Sunday matches. He's doing things he's interested in – including voluntary work at Coombe Country Park.

But it wasn't always like this. When Gordon, a Grapevine Help and Connect worker, first met him, Kevin wasn't doing much and was frustrated. Other teenagers would pick on him. Sometimes, Kevin would lash out at them. He had volunteered at a youth centre but had given it up when he couldn't stand the bullying any longer. His self-confidence had hit rock bottom.

A passionate interest in football was Kevin's ticket to a more fulfilled life. Gordon says 'Kevin's confidence and maturity have grown. He's got a captain's qualities now. He involves the others – makes sure they get a fair kick. They look up to him and imitate what he does.'

Asked about Grapevine, Kevin gets straight to the point: 'Gordon has helped me get more confident, do stuff.' Kevin's dad sees the benefits, too. 'He doesn't rely on me as much and it keeps him away from the people who were causing problems.'

IMPACT

In 2011, Grapevine supported 22 people in the Access to Sport project.

Between 10 and 12 people go each week for football coaching by Coventry City's Sky Blues in the Community at the Alan Higgs Centre. After the sports coaching, we offer sessions that help people to think about important issues like money, mate crime and keeping healthy.

A further ten people have one-to-one sports buddies – volunteers who join them to follow a sport or fitness activity that both want to try.

We have also delivered training to sport clubs in the region about how to welcome people who have a learning disability.

GRAPEVINE PROJECTS

All Grapevine projects are based on the commonsense principles described in this report.

THE PROJECTS:

ADVOCACY helps people to get their voice heard if, for example, they want to move home, have a formal meeting or have suffered abuse or neglect. You can see a film about Grapevine Advocacy: www.grapevinecovandwarks.org/advocacy-film.aspx

SELF-ADVOCACY Our team supports people to find their own voice, to campaign and have more of a say in their services.

ALL MEANS ALL offers advocacy and planning support to young

people and families from Black and Minority Ethnic groups aged 14 to 25. There is an external evaluation report about All Means All on the Grapevine website: www.grapevinecovandwarks.org/all-means-all.aspx

CONNECTING PEOPLE helps people to build strong networks of friendship and support by connecting them to others in their community.

GET IN helps young people with a learning disability get out more, have a say in their city and enjoy an ordinary teenage life. Grapevine youth work is





highlighted as a cameo of good practice in anti-bullying research by Cambridge University funded by the Department for Education. You can see the report at:

www.grapevinecovandwarks.org/cameo-of-practice.aspx

PERSON-CENTRED PLANNING

offers planning support to young people and families getting ready to leave special school.

QUALITY CHECKING is a team of people with learning disabilities. Grapevine supports the team to inspect homes and day services and make reports to City Council Commissioners.

THE H TEAM is made up of people who have learning

disabilities. They support others to have better health. They offer healthy lifestyles training; easy-to-understand information leaflets on health subjects; training for health services staff.

HELP AND CONNECT supports people to make connections and use ordinary services. There are one-to-one sessions that help people to get over problems, find support and get connected. There are also groups that help people build up their skills and confidence.

ACCESS TO SPORT This project helps people to create a healthier lifestyle and connect to others through sports and fitness-buddying.





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