



Friendship

a guide to finding friends and
building community

by Kay Mills



The Centre for Welfare Reform



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Introduction

In my life I have been very fortunate to have had parents who were very forward thinking for their time, and friends who have stuck with me through thick and thin. They have not always agreed with the path I have chosen to follow (I have my own unseen disabilities) but they have remained non-judgmental and always supported me. I have also had friends and colleagues who have shown so much faith in me; I have been overwhelmed by their enthusiasm for my work.

This support and belief in my potential has made me determined to support others who might not have had the same opportunities as me to flourish, grow and reach their potential regardless of their disability.

It is my great fear that some day I might not be able to communicate effectively and won't be able to tell people what I want to do and how I want to be treated. I am an individual. I don't like big gatherings. I don't like holidays in the sun, I like the snow. I don't eat meat, but I do eat fish (I need to work on that one). I love motorbikes and cars – I am a thrill seeker. I also have a quiet side where I love to sit in a field by a stream and listen to the cows and lambs munch and bleat. I love being outdoors. I love reading, but only factual books and writings. I am not overly fond of children; although I do have a few special people in my life.

I have recently been working in care homes where I have met people with no identity other than their medical history. I hope and pray that this is never me or anyone I know and strive to change this situation for everyone in general.

This paper is a collection of personal stories and strategies that I have used to communicate with people (some with complex behaviours) in order to understand what they want in their lives and how to support them to make friendships, experience new activities and connect them to the community, as well as maximising their potential.

I hope this paper will give you some practical ideas and motivation to continue to be creative in your thinking. This work, as we all know, is not easy; but when something works, then the outcomes can be amazing.



1. Looking Backwards

People with learning disabilities have experienced abuse, discrimination and worse. Often they find they are deprived of ordinary opportunities to be part of community life and to form friendships. However people with learning disabilities can make great citizens and form wonderful friendships and loving partnerships.

We often take for granted our right to be part of the community, to form friendships, to fall in love or be part of a family. But people with learning disabilities have experienced a mixture of discrimination, prejudice and institutionalisation which has deprived them of these basic rights.

Today many people are still institutionalised or they are not supported when they are younger to form friendships. It is important to understand the background to these problems; but also to see that these problems can be overcome. As we will see - even people who have been cut-off from the community for decades can form friendships and develop a rich and varied life.

Attitude towards disability

In the nineteenth century, people with learning disabilities or the 'feeble-minded' as they were known, were regarded as a threat to society. It was a common view that people with learning disabilities were uneducable, unemployable and a drain on the economy. They were not seen as having any value or worth or seen as able to contribute to society. In general there was fear that these 'feeble-minded misfits' would have a negative effect on society's gene pool.

Some came to believe in eugenics, which the The American Heritage Dictionary of the English Language defines as:



“The study or practice of attempting to improve the human gene pool by encouraging the reproduction of people considered to have desirable traits and discouraging or preventing the reproduction of people considered to have undesirable traits.”

The practice of eugenics was widely adopted by many countries including: Britain, Sweden, Finland, America, Austria, Australia, Belgium, Canada, France and Germany to name but a few. Sterilisation was one element of eugenics and was adopted by many countries. In Canada 2,832 sterilisations had been performed before their Sexual Sterilisation Act of Alberta was abolished in 1972. Between 1934 and 1976 a total of 62,000 Swedish people were sterilised, 90% of whom were women.

People in Germany, identified as having a ‘life unworthy of living,’ were sterilised against their will. More than 400,000 people were sterilised including criminals, the ‘feeble-minded,’ homosexuals, the idle and the insane. The Nazi Government went on to kill at least 250,000 people with disabilities; this was the first step in what we now call the Holocaust.

In Britain, between 1913 and 1959 segregation and confinement was the chosen path for legislation (the Mental Deficiency Act 1913) however, there were many influential people within the government at the time who supported eugenics in principal and would like to have made sterilisation compulsory for all people with learning disabilities and others who were marginalised. Asylums were built to house those bound for confinement and segregation.

The institutional building

Asylums or ‘mental handicap hospitals’ were predominant in the 18th, 19th and 20th centuries. The buildings themselves were usually hidden in the countryside with a sizeable amount of landscaped land around them. Some asylums housed over 3,500 people at one time.

The buildings themselves were often built in a ‘colony’ design which originated from America. The design consisted of small groups of wards grouped together within the same building, effectively creating isolated communities within those wards. Each building was linked to the others, creating a web like maze of corridors. Male



and female patients had separate wards which could often accommodate 60 or more patients at one time. Patients were guarded by staff at all times to ensure that segregation laws were met. Staff were not usually recruited locally, thus leading to further isolation for patients from their local surroundings.

The asylum was a community in itself with the able-bodied male patients working either in gardens or on the farm which was part of the asylum. The women tended to work in the laundry or in the kitchen. The patients with 'difficult behaviours' were locked up either in a single padded cell or in strait-jackets.

There was a culture of power and control and people had little or no choice regarding any aspect of their lives. From food, clothing, family and friends visiting, time to go to bed - everything was dictated by staff and everyone had the power to reprimand the patients, from the doctor to the handyman. Abuse from staff and other patients was not uncommon and many patients lived in constant fear.

But, now in Britain and many other countries things have changed and asylums have all but disappeared, and most people who lived in them now live in the community.

Moving out

The transition from life in an institution to life in the community is for the most part a huge improvement; however it does not come without its difficulties.

Around 1989 I was involved in supporting a young gentleman who was moving from a large institution to a house of his own. Our first meeting was at the hospital where he was living. I was offered little background information on this gentleman other than his medical history, and the fact that he could only say four words.

As I walked along the corridor to meet him there was an overpowering smell of urine and bleach. The nurse, who accompanied me, insisted that this was not a good move for this gentleman as he would never be able to cope in the community since he could do virtually nothing for himself.

I was shown into a communal TV room which provided no privacy for our meeting. Neither the gentleman nor I were offered an introduction by the member of staff and I was left to my own devices. My new friend, who was sitting facing a corner playing



with large building bricks, did not acknowledge that I was in his presence. I noticed on several visits, that the staff would randomly take the building bricks away from him and did not offer him anything else in return. This caused my friend to bang his head ferociously with his fists. Consequently, the same member of staff would reprimand him for his behaviour and threaten a punishment.

I continued to visit until we had built up a good rapport and then suggested that we could go for a walk. This seemed to go down well as my friend got very excited. I asked the staff to assist me to get my friend's shoes and coat. This request seemed quite a problem as the nurse did not seem to know where his shoes were. After about 10-15 minutes my friend arrived with his shoes on. Off we went on our first adventure. After about 10 minutes into the walk my friend started to limp. We stopped and I checked his feet, both were bleeding; they were red, swollen and painful with large blisters. I checked his shoes and found that they were not his, but another man's (the name was inside the shoe) and the shoes were at least 2 sizes too small. He had to return to the hospital in his stocking soles. Mission abandoned.

Our next venture started in a similar way but this time the staff could not find his jacket. The problem with finding clothing seemed to stem from clothes being kept in a communal wardrobe; for on the ward he only had a bed with a curtain round it and a small cabinet. After another long wait, we were off again: correct shoes and now a jacket. A short walk brought us to a local café. On the right hand side, as we entered, was a glass cabinet with cakes in it. As quick as a flash my friend grabbed the glass cabinet and ripped it off the counter to which it had been bolted. He was shouting "cake, cake". The café emptied and children were screaming. As calmly as I could I asked the assistant to give me six cakes as quickly as possible. I apologised profusely and offered to pay for any damage and tried to explain that no harm was meant. The frightened assistant almost threw the cakes at me from behind the counter. We left hurriedly, with my friend cramming his mouth with all 6 cakes. He munched his way back to the hospital. It was only then I remembered that one of the four words he could say was "cake".

It appeared that in the hospital people never had the chance to choose their food. Everything was given to them. They could take it or leave it. Any food they did get they ate quickly before someone else stole it. Consequently, if people had to wait for food this caused problems, as did having to wait in a queue because the



food was always served at the table. They lacked social skills as they had not been exposed to normal everyday community life. Men and women were also segregated so communicating with the opposite sex and the formation of relationships was a daunting prospect.

Facing the challenges

From this day on there were many challenges for my friend and a lot of learning, listening and adjusting to life in the community.

One of these many challenges was trying to reconnect my friend with his family. His father and mother visited him religiously every Saturday (at cake time) but his brothers and sisters and other relatives were scared and uncomfortable visiting in the hospital. The communal living room was the place you met your family and other patients, who did not receive visits or had lost contact with their relatives, would vie for their attention.

Another challenge is isolation. You can have a lovely house and a change of surroundings but you can still end up living in a mini-institution. There is a risk that people can become more isolated than they were before. In the hospital people may have had friends, they might have been employed or they may have been part of the hospital football team. When people move out and into the community they can lose their identity and the role they played within the system which was the hospital. There they were accepted for who they were physically and mentally within the confines of the hospital. Out in the community, many people have to begin from scratch. People might now live in a different area and friendships could lapse if there is no support to maintain them.

Another possible challenge may be the area the person has moved to. Neighbours might not like having 'one of those people' living next to them, through fear or ignorance. Others might think that their house should have been allocated to a more suitable candidate who is seen as having a greater input into the community. The community might also have its own prejudices and be less tolerant of people with disabilities, who take longer to get in and out of lifts and may take longer at the checkout.

Carers must also be continually mindful that they may not always 'know what's best for people' and may impose their values on the individual, albeit it often with the best possible intentions. If we forget this we can create mini-institutions within the person's own home and community.

Getting a life

Regardless of the challenges which are imposed upon people, **if we believe in people's potential, great things can happen.**

When my friend left hospital, he moved into a house in a completely different area to where he was living before. He was gradually introduced to his new staff team, who had been specially matched to meet his needs and personality. This meant lots of fun, cakes and at times the stress of getting to know one another. As time went by, my friend became more comfortable and confident in his surroundings. Staff had used their own networks and introduced him to people and activities they attended. A social life was evolving! He knew the neighbours; people spoke to him by name, his family visited for dinner and vice versa. Things were looking good.

We met up again at this point to discuss 'What next?'. We did some planning and looked at what was important to him and what he loved to do, then the team and I went off and worked on an action plan. To cut a long story short, he ended up working in an office doing mail shots, hand over hand, for an hour or so a week. Soon the employer realised that his input was really making a difference to the office and he was offered more hours. Next, he was given his own desk, then the pin code of the building and finally he was put on the pay roll.

Not bad for a man who supposedly wouldn't cope with living in the community!

Since then life has continued to blossom for my friend. I see photographs of him on Facebook. He has been abroad on holiday many times and enjoys eating out and having a few drinks. **He has a fun filled life with a future.** He still loves cake but now, he is more likely to have bought you one and be offering you a piece first.



2. Looking Forwards

Although there are still many challenges facing people with disabilities today we have also made some real progress. If we approach problems in the right way, with optimism and creativity, there is no limit to what we can achieve together. Here is a more recent example of what is possible.

Lewis's story

I was recently working with a young autistic man called Lewis. As a child Lewis presented his mother with many challenges, which many parents of children who are on the Autism spectrum will identify with. Lewis' mother Gillian wondered if Lewis would ever have a future. It was not an easy journey for his family, as she told me:

“He was a nightmare Kay. He had severe developmental delay and flapped his hands all the time. He wouldn't wear clothes and ran about naked; he even stripped in the supermarket and streaked. The police were even called a few times. He constantly ran away or he would sit and rewind videos. He used to kick, bite himself and would smear faeces over his room.”

Lewis was then 16 and had developed a keen interest in music. His social worker had put him forward as a candidate for a new pilot project for self-directed support. Lewis was successful in his application and, as part of the self-directed support pilot implemented by East Ayrshire Council, he was awarded £250 to be used to meet an outcome in his support plan. Lewis chose to have an independent broker from the Community Brokerage Network to help him and this is how we first met.

Lewis decided he wanted to learn to play the accordion and wanted to use his £250 to pay for accordion lessons. I met Lewis and his mother at their house to discuss how we could move things on further and also to give me the opportunity to get to know Lewis better. Lewis was keen to let me listen to some things he had composed by himself. His compositions were good but the quality was poor, as he was using a very old laptop so the sound was not at all clear.



Lewis's mother went on to explain that Lewis had learned all that he knew by watching YouTube. He had never had a music lesson in his life. As the conversation went on Lewis's mother said that one of his latest compositions was on YouTube. The piece was being played by the Ayrshire Symphony Orchestra for their Christmas performance and Lewis was also conducting it.

Apparently Lewis had been at a Burns Supper and was sitting next to John the conductor of the Ayrshire Symphony Orchestra. They began talking about classical music and Lewis' love of it. John invited Lewis to their next rehearsal.

Lewis arrived at the rehearsal with his mother. He had a bundle of papers in his hand and his mother asked him what the papers were. Unbeknown to anyone Lewis had prepared full scores for the whole orchestra of "Melody on the Railway". He started handing out the scores, much to the amazement of everyone. The orchestra played Lewis's music and were impressed by its quality. They continued to meet and it soon transpired that Lewis was also a gifted conductor.

I went home and watched the performance on YouTube. It was amazing. I knew he was good but now I knew he was in a league of his own. His potential was incredible and I was astonished that his musical ability had not been taken further even after the YouTube viewing. I was also intrigued to find out that the school did not have music as part of the curriculum, so it was little wonder that his gifts had not been encouraged at school. He had been attending drama classes which he loved but (to my knowledge) his musical talent had not been recognised to any extent. To me it felt as if Lewis had outgrown his peers and needed much more of a challenge. Lewis's mother would later confide to me that she felt the same but no one else seemed to have noticed. In my head I was already planning a future for Lewis. I knew he could go far.

I started to do some research with regard to accordion lessons for Lewis. Things were not that simple however, as I soon came to realise that you needed to buy your own accordion first before you could have lessons.

I eventually sourced an accordion shop, which was not that easy to find. When I spoke to the owner I realised that accordions can cost thousands of pounds and that the cheapest one he had was £500. He said that it was rare to find one of this quality and be able to sell it at that price. I was devastated and phoned Lewis and his mother



to explain the predicament. Lewis's mum said that Lewis always got money for his Christmas so could use that along with the £250 to buy the accordion if it could be kept until after Christmas.

I phoned the owner and asked him if he could keep it for us? He said absolutely "no way", that this accordion would fly out the shop as it was such a good buy. I explained the story of Lewis and how gifted he was and pleaded with him to help us out.

The other problem was that we could not get to the shop for Lewis to try it out for size as the shop was quite a distance away and Lewis's mother could not take him there due to other commitments. I explained this to the shop owner. He eventually said "Ok, where does he live? Would it help if I took the accordion to Lewis?"

I jumped at the offer. The shop was 39 miles away so it was a very good gesture on the part of the owner. He was putting himself out quite a bit for us which I appreciated very much.

A date was set for the trial of the accordion. I was on a day off and was out hill walking with friends. I was just wondering how things were going when the mobile rang. It was the owner of the shop. He said that he hoped that I didn't mind him phoning me but he had just left Lewis's house and he was eager to talk to me.

Apparently Lewis immediately picked up the accordion and started to play. The shop owner who was an accomplished accordion player and musician was astonished at this and was impressed at how well Lewis could navigate the keyboard. I had already provisionally set up some accordion lessons for Lewis but the shop owner suggested a friend of his, who lectured at the Royal Conservatoire. He felt that with his talent Lewis would benefit from specialist tuition.

We were thrilled with this proposal and Lewis began his lessons with this lecturer. I continued to focus on Lewis's passion for music and his eagerness to learn. I was looking through the prospectus for the Royal Conservatoire and noticed a summer school course on composition and conducting which I knew Lewis would love. But Lewis would have to wait until he had saved up for that.

However, due to his newly exposed talent, Lewis was granted a further £5,000 to his individual budget to enable him to progress with his music. Lewis decided to use this money to purchase new recording equipment and computer software. My colleague



Barbara, who was helping us, managed to get a fantastic deal which meant that we now had enough money for Lewis to attend the summer school as well.

I phoned the Conservatoire and enquired about the course. I was told that people attending this course normally had to have music qualifications already and that anyway, there was only one place left and the closing date was in the next few days. I explained that Lewis had an exceptional talent and pleaded with her to look at his video of “Melody on the Railway”. She didn’t sound too hopeful but said she would look at it and phone me back.

The girl phoned me back and said that Lewis had a remarkable talent. She had shown it to the course tutor who was prepared to consider Lewis for the last place if Lewis could send a portfolio of his compositions and any other work he had completed. I phoned Lewis’s mother and told her what I had found out. I was also relieved that a buddy would be allocated to Lewis to help him find his way around the building and would make sure that he had support in the class, should he need it. The Conservatoire took Lewis’s Autism in their stride and embraced him as the unique and talented individual he is.

I was anxious about how Lewis’s mother would respond. Did she think it was too early or rushed? Lewis had never been away from home on his own before. Thankfully, Lewis and his mother felt the same as me, that this was a great opportunity and we might never get it again.

I helped Lewis and his mum with the application. This took hours on the phone and we had to forward video evidence of his ability and organise a reference from colleagues in education. But eventually Lewis was given the last place available.

Lewis’s social worker, the senior education manager and I worked together to facilitate Lewis attending each day. Before Lewis started his course we were all invited to a tour of the Conservatoire. As we walked along the corridors with all sorts of music streaming out of the rooms Lewis turned to his mother and I and said “This is music heaven”. Lewis finally felt he was in the right place. It was a huge success.

Lewis is now studying towards a Degree Course in Composition at the Royal Conservatoire of Scotland and has been commissioned by various organisations to compose various pieces of music for which he has been paid.



The challenges we faced

What were the challenges?

- Lewis did not have the relevant qualifications!
- How could we pull together a portfolio so quickly?
- How would Lewis cope in a new environment as he has Autism?
- Lewis might not want to attend!
- Lewis might not want to go on his own as he had never done anything like this before.
- His mother might have felt that he was too young!
- Where would we get the support to get him to and from Glasgow every day for a week?
- The course might be at too high a level for Lewis

What made this work so well

- Insight
- A belief in Lewis's potential
- Positive thinking!
- Working and acting quickly- grasping opportunities
- Maximising Lewis's potential, by exposing him new opportunities
- Getting to know Lewis and his mother well enough to make an informed judgment of their responses.
- Persistence and focus on the outcome!
- Not taking 'no' for an answer at the first refusal or obstacle!
- Thinking of solutions and not being fazed by negativity
- Finding out what is possible first before considering any obstacles!
- Exposing Lewis's talents to people who can make decisions
- Asking for 'help' from colleagues and others who knew Lewis well



Lewis is now on his way to a very bright future. He is now a student and a composer, has new friends, is earning money and is doing something he loves. Lewis is also a contributor and conductor and students have been queuing up to talk to Lewis for advice and discussion with regards to his techniques and arrangements. As Lewis said:

“This is music heaven.”

It would have been so easy to miss this opportunity but I am so pleased we didn't!



3. The Value of Community

Being an active part of our community can bring so much richness to our lives and that of others. It can be the key to our ongoing education and the exploration of new skills, hobbies, activities and relationships. It can help us find our identity and raise our feelings of self-worth.

The benefits of membership

The value of community membership is not something that most of us think about in any great detail. However, if we look closely at the positive impact it has on our lives, we can see that it has great influence over our thoughts, feelings, attitudes and friendships through the different roles we embrace in our community. Not only does it have an impact on ourselves but it has an impact on how others view us in terms of the positive contributions that we make to others and the community itself.

In my community I am a member of the local folk club. I have been going on and off for over 30 years. In this setting I am extremely relaxed. It is one of the few places where I am happy turning up on my own. I am known by name. People will ask me to join them at their table. I do not feel out of place. The club organiser is a friend of a friend and we always have a chat about who is coming to play at the club in the future. One member in particular, Davie always has a very loud and welcoming greeting whenever he sees me.

I feel good, and a part of this group. We all have a common interest. Some are more passionate than others. I have been given a bodhran (an Irish drum) as a present and Davie, who plays this instrument very well, has offered to teach me. I have had no success as yet, but I feel involved, welcomed, able to participate and generally comfortable and accepted.

At the club, I was drawn to a couple who had two black Labrador dogs with them. I am an animal lover and was immediately drawn to the dogs. I went over and went



to stroke the dogs. The couple, who owned the dogs, were in fact, blind – a fact I had failed to recognise. We chatted about the dogs and became quite friendly.

I learned quite a lot about how it was to be blind and what the difficulties were. This couple really impressed me, as they never let their disability hold them back and they visited folk clubs all over the country. For instance, I learned about socks and how, if you are blind, it is better to have them all the same colour as pink and yellow socks worn at the same time might draw attention to you.

As I got to learn more about my new friends, I realised that the club had adapted quite considerably to my friend's needs. Chairs at the front are always reserved for them as it gives everybody more space. There is always a free arm to guide them to the bar or wherever they need to go. The dogs are provided with water bowls, and nobody minds waiting a little while longer to get into their seat if they are behind them. The club has made the venue accessible for them personally. There is no great fuss or attention drawn to them because of their disability and these adjustments have been made almost subconsciously.

Friendship and networks

The couple says that if it had not been for the welcome and friends they had made at the club, their lives would have been very different from the one they have now. They would be very isolated. There are more benefits than friendship. People look out for them. If they want to go to another club or concert, they will phone ahead for them and check that someone will be there to welcome them and that a seat is reserved etc. If they were ever having a problem with something or maybe just needed some information, the network contacts within the group are vast e.g. the organiser is the head of leisure and recreation at the council and another member has a shop etc.

I have also found that because of the club's knowledge and acceptance of people with disabilities, when I took a man with a learning disability along, the group welcomed them. The blind couple were the first people to ask us over to their table and to make conversation. Over the weeks, they kept a place at their table and would remember what was going on in my friend's life. We would enquire what they had been doing. When they went on holiday they brought him back a present.



Learning from each other

For me, one of the best things that happened was that they invited him to their house for tea which was a great success. He invited them to visit his house and a firm friendship began. This friendship not only gave this man company, he also gained many new skills. He began to take an interest in different types of food as he began to mix with other people. He also developed much better communication skills and had a wider range of topics to discuss due to being in different people's company. The benefits to him were immense. The group also benefited from our visits as there was a huge rise in the sale of crisps and drinks. He was a very good customer, who had also become a member.

The key to the success of this man joining and being part of his community stems from the in-depth planning which staff did with him before they ventured out.

You will hear me talking about planning and its importance, but I would like to reinforce this point, as it is crucial to people's success in joining and being accepted in the community. The fact that this man had a genuine love of music, and also this type of music made it much easier for him to join this group. People could see and would comment favourably on how he jumped up and down in his wheel chair, singing (his version of singing) and clapping. He made people smile and warm to him as they shared the same enthusiasm for the music. He did at times make loud noises at quiet times and talked when we were supposed to be listening or waved to someone across the room when a very sombre song was being sung, but it was okay. He was a kindred spirit.

If we analyse why this particular connection was such a success it is clear that if great care had not been taken to find out what gave this man a 'buzz' (through good planning) and his personal assistants had just taken him along to things that they were interested in, he would not have had the same enthusiastic reaction. This in turn would mean that he would not have expressed it to other members and there would have been less chance of him being accepted into the group.

Remember, there is no point in just being 'in' the community you must take an active part.



Sexuality and the power of hugs

For many of us having a special person in our lives is important to us. The trust, warmth and comfort of being with someone who accepts you for who you are, is vital to our happiness and contentment.

According to research, a hug keeps tension away and embracing someone special can lower blood pressure. In one experiment, couples who held each other's hands for 10 minutes followed by a 20-second hug had healthier reactions to subsequent stress, such as public speaking.

Compared with couples who rested quietly without touching, the huggers had:

- lower heart rate
- lower blood pressure
- smaller heart rate increases

[Source: Grewen KM, Anderson BJ, Girdler SS, Light KC. Warm partner contact is related to lower cardiovascular reactivity. *Behavioural Medicine*, 2003;29:1]

So why is it that in some cases we seem to find it so difficult to accept that people with learning difficulties need and feel the same as us? Why would it be any different especially when research shows us that it is so good for us physically and mentally?

Jim's Story

A few years ago I was looking at how we could make the review process for people with learning difficulties less stressful and more person centred. I was asked to work with Jim who was due to have a review. I was told that Jim had been in 'their service' for many years and did not say much at all.

As I started interviewing Jim it became apparent that he had a girlfriend who seemed to play a big part in his life. It was not going to be successful just interviewing Jim himself, I was going to have to interview his girlfriend, Jane, as well.



As my interviews with the couple continued (it is all on video) it became clear that they had a very strong and loving relationship. They cared about each other and understood each other in a way others would not. They enjoyed each other's company and longed to spend more time with each other on a more intimate level. They said good night to each other on the phone every night.

When Jim was asked how he would feel without Jane in his life he said "lost" and when Jane was asked she replied "sad and lonely".

They talked about marriage and what it would be like and what each other would wear. How would they arrive at the church – in a limo or a horse drawn carriage?

They wanted to have more romantic dinners and go out as a couple with other couples. At the present time they only saw each other once a month and that was in the company of Jim's family, and on every other month Jim stayed at Jane's flat for the day and they had a romantic meal together.

Jane said that they had got engaged. Jim had given her a ring which was engraved and it was beautiful. They had an engagement party but Jim couldn't make it. The party went on without him!

The couple talked fluently and without hesitation.

In order to move things on, I asked the couple if they would like to tell staff and family how they felt about each other. I thought that with the support of staff and family we could perhaps help Jim and Jane achieve some of these goals. They agreed.

The first viewing of the video was with Jim's parents. The atmosphere was tense as Jim and Jane were embarrassed. Mum and dad were uncomfortable, and mum ended up in tears as she realised that she never imagined her son would have the same feelings for someone else as she had with Jim's dad. She recognised that she never thought that the relationship had so much depth. Jim's dad said that he knew it had to happen someday but had tried to put it to the back of his mind.

When we interviewed Jane's staff they said that they didn't know much about Jim, they had "never asked". They were astonished, as were Jim's staff, at the loving relationship the couple had and they didn't even know about it.



Staff said that they would carry out their daily chores as support workers, but never thought to ask the person about their dreams, hopes or who was important in their lives. They admitted that they only paid a tokenistic acknowledgement of a relationship, if they knew about it at all.

My questions were not out of the ordinary. I am sure that most women have sat with their friends and discussed dreams and any special person that was in their lives, or who they would like to be in their lives and how much they loved to be in the person's company and so on.

Many people with disabilities do not have the opportunity that most of us do, to discuss their feelings and thoughts. So they remain quiet and withdrawn and do not discuss or ask for advice about one of the most fundamental things in life.

Maybe this is not our job. So whose job is it then?

Thankfully after a planning day with friends, family and staff invited by the couple, the group began to realise that they were not thinking about people with learning difficulties having relationships in the same way as they would for themselves. This was unfair and unbalanced.

From this point on family and friends supported the couple to achieve most of their goals and dreams.

This included:

- Having a nominated person of their choice to discuss intimate and personal thoughts and anxieties with
- Spending more time alone
- Going out with another couple. Jim's brother put his name down for this!
- Spending the weekend together on their own, staff and family supported this
- Going out for meals
- Playing pool
- Watching a live football match
- Planning to get married



The impact of this work led to service providers rethinking staff training to highlight the importance of friendships and relationships. Staff's role would now include much more in depth practical and emotional support than before.

If we don't ask the right questions we can't support people's passions.



4. Finding Community

If we are to successfully support people to be active members of the community we need, first of all, to understand what practical steps we can take to maximise the opportunities people have to make positive connections.

Most communities are buzzing with activities which we may have never heard about. We generally only look for a particular hobby or activity that we know interests us and do not explore what else there is on offer. To get to know what is going on in our communities, we need to ascertain what is there already and then gather further information about other opportunities which are available to us. Getting to know how to gather this information and then how to initiate an introduction has to be carefully planned in advance in order to ensure a positive outcome.

Mapping community

Community mapping involves recording all the places that are in the local area that you know of. You can build up the information of the map as you find new places to visit which might be of interest to the person you are supporting e.g. clubs, pictures, parks etc.

There are many ways of gaining this information. For instance, you might employ someone or ask the help of a person who is a community 'bridge builder'. The bridge builder is someone who is naturally good at resourcing and sourcing information and retaining it. They normally have very good communication skills and are not afraid to ask questions. They are good at linking people to the community. These people do not need to be a local to perform well.

There are usually people like this in the community already. For example, if you ask people: "Who can help me to find out about such and such?", the reply will often be along the lines of: "Oh ask Mrs Brown, she knows everything that is going on and if she doesn't she will find out for you!" These people are always well connected, take



an interest in what's going on (some people call it being nosey) and usually take part in many things in the community. All communities have a "Mrs or Mr Brown". My Mrs Brown is a member of the church, a Justice of the Peace, breeds dogs, runs a youth club and is renowned for her fabulous steak pie.

You can also find out what is going on by buying a local newspaper, looking at the council website under 'what's on' or under 'clubs' and 'leisure activities'. It is a good idea to sign up to receive newsletters from as many different groups you are interested in as possible to give you a choice of new opportunities coming up. Go into local corner shops which usually have a notice board of activities going on locally, check out church notice boards or get the newsletter. Parks and wildlife centres also have events which are on throughout the year such as bat walks, talks identifying trees and the habitat of different animals and birds. One wildlife park near us also hosts the local 'geocaching' group. Geocaching is an exciting outdoor adventure for groups and families. It's a modern day treasure hunt for the digital generation, where you can enjoy the freedom of being outside and discovering new places. The geocache is a small waterproof treasure box hidden outdoors. You use your mobile phone to guide you there. It's a great way of meeting new people and having fun outside.

Once you have identified where the person you support would like to become involved with, it is useful to go and check out the place first of all before becoming a member.

Go along and take note of how you are welcomed:

- Was it friendly, or did it feel that it might be a clique?
- Were you given information about club nights?
- Was information given freely?
- Were you invited to sit with anyone or were you left on your own?

All these things can give you a good idea of what it would be like to join the group on a permanent basis.



It is also quite important to find out the culture of the group:

- Are there any particular things that people do or prepare for each week?
- Do people take it in turns to man the coffee bar or do people have particular seats that they sit in every week?
- What is the dress code?
- How much does it cost?
- What are the facilities like and do they have a disabled toilet?

Making introductions

Once a decision has been made to attend an activity, it is extremely important to pay attention as to how you introduce the person you support to the new group. It must be made clear from the beginning that it is the individual who is interested in the group and that you are only there to support them.

Practical gestures can be used to reinforce this e.g. If someone tries to talk to you and asks about the individual you are supporting, suggest that they ask the person themselves. Think about how you position yourself. Make sure that you are not in front of the person and blocking conversation. Always involve the person and direct the conversation to them. If the person is in a wheelchair, try to get to the same level as them to talk to them, don't tower over the person.

Don't introduce yourself as a personal assistant, or mention that the person you are with has a learning disability, as this immediately changes the power balance between the person and yourself to others in the company. Either don't say anything or say they are a colleague or friend of yours. Remember to be polite to the individual at all times but especially when in new company as this sets the tone of respect for the individual in the group. If others see that you are respectful they in turn will usually reciprocate.

Respect works both ways. Time needs to be spent supporting the individual to polish up their social skills. Good manners go a long way.

When it has been decided that there is a particular place or activity the person wants to join it is important that they go to the place regularly. It is the only way people get



to know us and build up a rapport. If we only attend once or twice we will not get to know people and we will also not be seen as being enthusiastic. People will not be so likely to strike up a conversation etc.

If I think of all the places and situations I have been in, where I have made friends, it has been when I am doing something regularly e.g. I walk my dog every night with a friend. We have been doing this now for over 15 years and it all started when my dog was a puppy. I was training him in the local park. We went there every day at the same time to the same place and practiced. One day a lady who I had noticed running every morning, came over and asked if my dog was a Bearded Collie. We started chatting. She had just lost her old dog which was of the same breed but, apparently, still had another dog back home. She said that her husband would love to see my pup and said that she would bring them along one day. We met one morning shortly after this and we got on really well. We introduced his old dog to my pup and that was the start of regular dog walks together. We now have the keys to each other's houses and help out when needed. Our shared interest and regular meetings fostered the makings of a long and lasting friendship.

Building new community

There are many other ways people can become involved in their community. If there is a particular hobby or interest which you cannot seem to find available in the community, set up your own.

I was working with a young visually impaired gentleman a few years ago. His support staff were struggling to find things that he was interested in. This problem was compounded by the fact that he chose not to speak to anyone except, on occasion to his mother. As I got to know this gentleman over the weeks I noted that the one thing that he loved to do was thread sewing reels (bobbins) onto a string. This gave me an idea. Would this man be interested in making jewellery? The support staff thought this was a good idea so we decided to give it a go.

The staff bought a jewellery kit to start with to see if he was interested in it. He was, but the beads in the kit were too small and fiddly for him. So we bought larger ones and he started threading them with no problems at all. He loved it.



From there I sourced free workshops that the young man and his personal assistants could attend which taught them the process of making clay beads from start to finish. All staff attended so that everyone in the team could support him with this. This course was a success and he loved it and so did all the staff, who received gifts of the jewellery he made for them.

From here I took it a step further, and looked for a community venue where he could make and fire his jewellery on a regular basis. We found the perfect place, not in our town, but a few miles down the road. The art group met there every week and had all the facilities we were looking for. I made enquiries to the lecturer with regards to joining the group. Happily, we were given a warm welcome by all the members and he started making his jewellery there. The number of finished items started to mount up so the young man and his team decided to try to sell his work, which turned out to be very successful, he even had his own business cards.

From beginning to the end of this process, this young gentleman took on many roles including:

- student
- group member
- entrepreneur
- businessman
- friend

He was seen as someone who had talent and a gift that he could share. His new found community was not on his doorstep but only a few miles away!





5. Using Our Networks

Most people do not realise the wealth of knowledge, skills and connections our friends and family have between them. If we extend this to friends of friends and acquaintances we can imagine the colossal amount of information we have available to us.

We all have connections, but often we fail to think of them when we are in the support worker role. We either forget that the individual we support has their own natural networks or feel that it is inappropriate to enquire about them. However, taking that first step may mean the difference between moving closer to the individual's goal and continuing on a long drawn out process that could take months or even years to progress. Take the chance and ask!

Exploration

If I am working with a person who has a particular interest, hobby, activity or type of employment they would like to try or take part in, I always try to use **natural networks** as my first option.

There are several reasons for this:

- If there is a natural link and people either know the individual or yourself you have a head start to begin with. You do not need to go into detail about certain aspects or history of the person or why you would be asking for assistance.
- People are more likely to go out of their way to help if they know the person you are supporting and also yourself.
- People are generally more understanding and tolerant of people who have unusual or complex behaviours.
- It is easier to approach someone you know.
- They can introduce you to other people with the same interest or hobby.



- They can give you more suggestions of other contacts relating to the activity you are interested in.
- They can give you guidance re the relevant protocols for a particular activity or club.
- They can give you information about how things are run and what is the normal procedure which takes place before, during and after the event.

To start the process, I ask the individual to invite as many people as they feel comfortable with and who they know well to a planning meeting. I begin by drawing up a chart of their networks and build up, layer by layer, all the information.

For example, if I start with the individual's mother I might ask:

- What do you do for a living - now or in the past? **Book keeper**
- What are your hobbies - now or in the past? **Making cards**

As they answer the questions (and, if they look comfortable with this) I ask more in-depth questions that build on their answers:

- **Book keeper** – how long ago was that? What did it involve? What company was it? Are you still in contact with anyone from there?
- **Making cards** – how long have you been doing that? Do you go to a class or make them at home? Do you sell them?

I then go on to ask them about their sister, brother, aunt, uncle and then look at children and grandchildren. Don't forget, children have interesting hobbies too, and parents meet other parents while they accompany their child to those activities.

This has worked in my own life. Recently, my friend and I needed a little piece of advice from a lawyer. My friend knew that one of the other children's mothers was a lawyer, but only knew her to say "Hello". We felt that it might be a bit cheeky to approach her but that we had nothing to lose if we were polite and explained that we were not wanting a great deal of information and would understand if she did not have the time. We were very lucky - she said she would get back to us the next day and she did, with exactly what we needed, no charge. Result.



Networking works

As you go through all the people in the room (it can take quite a while) you build up a huge amount of information. For example, perhaps the person you support likes water, so maybe the brother who is a social worker and sails might have some links or ideas around a sailing activity or wind surfing etc. And remember, some information will be more useful than others, but you may still be able to use it in another situation later on with somebody else.

People will become involved directly by offering to assist you to join in an activity or they will offer information or put you in touch with someone who will be of more assistance (see Figure 1).

You should explain the process you are going to use briefly before you start and then people are aware that they can get involved as little or as much as they like. There should be no pressure; reassure people that the information itself is of great value, they don't always need to be physically involved in the process.

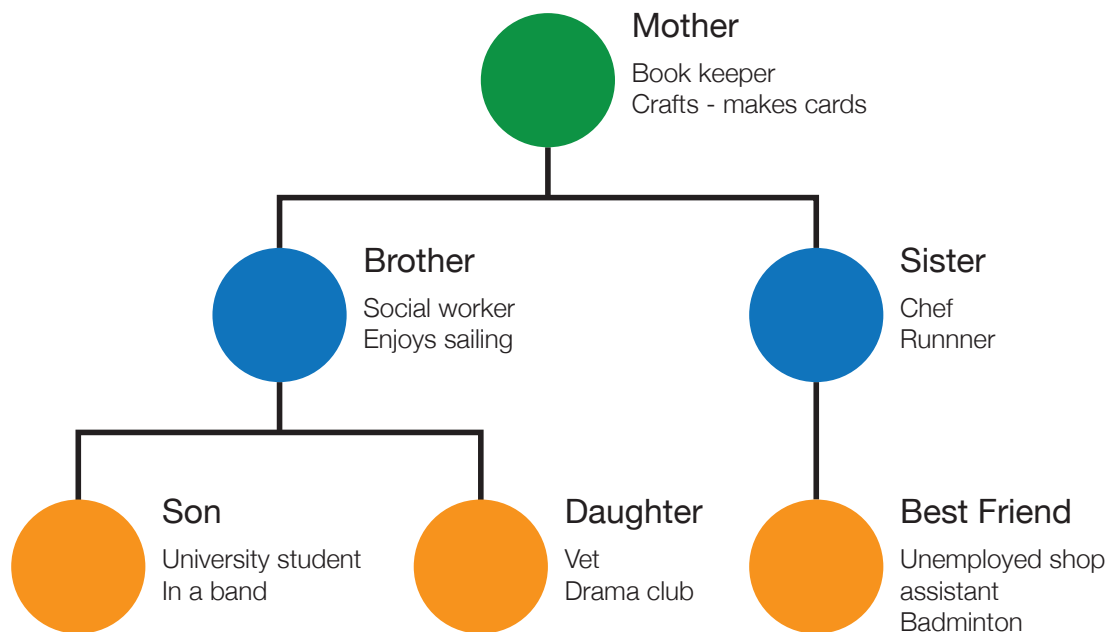


FIGURE 1. EXPLORING NETWORKS



Chris's story

My first meeting with Chris revealed a very frustrated, lonely and at times isolated young man. He was the eldest of two siblings. His sister, who was younger than him, had much more freedom in her life than he did and he felt that as the oldest son, his parents did not give him the respect (due to his disability) that he felt that he should have been given. His parents would ask his sister to help him with things which he could do perfectly well for himself. They were overprotective and did not realise how upset this made him feel. He was also very lonely, and did not have any friends of his own. Any friends that he had were friends of his mother and father. His frustration led to constant fights and battles with his sister and more often than not his mother.

I explained to Chris, that the only way forward was to let his family know how he was feeling, otherwise nothing would change and he would continue to be frustrated and his parents would remain oblivious to his anguish.

We began to plan, and at an appropriate moment, Chris told his parents how he felt. It was an emotional meeting but had very positive results for Chris. His parents had no idea that he was so lonely or his feelings with regard to his sister. His mother and father thought that family was enough, but clearly it wasn't and they committed to supporting him to realise his potential and dreams.

We used the method described in Figure 1 to start to work towards fulfilling Chris's ambition.

Through natural networks Chris:

- Started to travel independently to work
- Formed a special relationship with a young lady
- Became a 'runner' in his cousin's band
- Started working in his aunt's business
- Doesn't feel angry anymore
- Has new friends of his own
- Feels listened to and respected
- Is planning for the future and mum and dad have plans to buy him his own house when the time is right.



This process took less than 6 months to achieve through the family's natural networks.

The importance of friendship

As we can see from the previous case study, how important friendships are and how often and how easily its importance can be overlooked. There are many people in a similar situation to Chris, but they do not have the support of the family that he has. As a personal assistant, it is important to support people however we can, to maximise their opportunities to develop friendships. We can't force it to happen, but we can help things along the way. We are aiming for the individual to develop their own friendships and become less reliant on paid support or family for several reasons.

In the first instance, most people value the feeling of having a close friend who they can share all their thoughts and feelings and dreams with. They are someone who you can reveal your true self to, warts and all. A friend is someone who sticks with you through thick and thin and doesn't 'go off shift'. They don't think you are 'weird' when you have a panic attack, or when you won't leave the house without wearing your 'lucky underpants' when you are going for an interview.

Friends tolerate our superstitions and don't dare split a pole lest we split a friendship! (Some people will know what I am talking about). Friends bring fun and laughter into our lives and share a history with us on an equal level. They also share the tough times too!

Now, I am not saying that support workers cannot become the friend of the person they support. What I am saying is that, when someone is paid to support you, there are boundaries within that relationship due to the fact that the support worker is paid to carry out certain duties and to act and abide by those rules and constraints e.g. a support worker, possibly due to a contractual agreement will have to keep a professional boundary between the individual and themselves.

I have a friend who used to support a young man who lived in an institutional setting. They formed a friendship over the years and enjoyed each other's company. They laughed a lot.



As time went on the young man became very unhappy and upset with the environment in which he was living. My friend felt the same, and challenged the organisation that supported his friend and insisted that it was in the young man's best interest to be supported in a house of his own, in the community.

After a great deal of animosity, struggling and the loss of his job my friend secured a house for his friend. The downside was that the package was short by twenty hours a week and the young man needed twenty-four hour support. My friend volunteered to fill the twenty hour gap with unpaid support to make sure his friend's needs were met.

The difference in this relationship is in total contrast to the role of paid support worker. These friends call each other names, get drunk together, fall out, go in a huff, swear and slam the phone down on each other, eye up the talent, talk about sex, go on holiday together and generally have fun.

Both have gained from the relationship; they have made friends, gone to new places, linked in with each other's networks, spent Christmas together and so on. They have a history.

Forming friendships

There's no formula for forming friendships, but here are a host of top tips you can follow:

- Go regularly to the same places, at the same time to the same seat or spot
- Go to places that are welcoming and have a bit of banter (sometimes called third places): local pub, hairdresser
- Talk to people, ask questions
- Smile at people
- Offer to carry anything
- Bring your neighbours bins in, or out for them
- Say good morning
- Fix things even if you didn't break them
- Join the neighbourhood watch



- Bake extra and share
- Use local shops regularly and get to know the assistants
- Take part in community events
- Volunteer
- Have a BBQ and invite neighbours
- Get involved in anything
- Have a jewellery or candle party
- Compliment people
- Ask for advice
- Offer a lift
- Join a club that you're interested in
- Recycle items e.g. offer magazines to local hairdressers
- Collect for a local charity
- Use natural networks
- Think of people you have lost touch with and try to contact them
- Send cards to new neighbours
- Send cards for special events e.g Golden Weddings
- Make sure to brush up on your social skills - we want to draw people to us not push them away
- Talk to the postman
- Talk to people when you are in a queue (my friend met her husband this way!)

I know that trying to establish friendships for yourself can be quite difficult, let alone supporting someone else to, especially if you have a quiet nature. However, you can learn and make the process a little easier if you try to follow some of the suggestions I have mentioned above.

Another point worth making is that sometimes, for one reason or another, we may need to go outside our local community to 'join in'. Which I think is perfectly acceptable, as some communities are more welcoming than others. It is better to spend more travel money once a month to go to a club or hobby where you feel comfortable and are accepted, than to struggle every week to be accepted in your local café.



One person I know had this problem as he lived in quite a wealthy area. Neighbours were wary of Tim and did not like his 'minders' coming and going to the house. He had tried to be friendly, but things were not as good as they could have been. However, his support worker introduced him to his own club 20 miles away, where he played the fiddle every Tuesday night. Tim loves this group and he has made many friends there. He now gets dropped off at the club even when the support worker is not there and the group make sure he is okay. Tim also goes on holiday with other members of the group and visits the local vet who is also now a friend.

It might take a while, but don't give up, there are a lot of potential friends out there.



6. Sustaining Friendships

Long term friendships have a huge impact on our lives. They not only offer us companionship, they also have a positive effect on our mental health. Studies suggest that having strong social ties are the key to happiness. Other benefits are said to include: living longer, boosting our immunity and reducing the risk of depression. Making friends is not easy for everyone. It takes time and dedication on both sides to keep the friendship going. True friends are hard to find, so in order to have a good friend, we need to be a good friend.

In many cases the individual you support will rely on you to help them keep friendships going. This will normally involve you helping out with the practical aspects of supporting this friendship. For instance reminding people of friend's birthdays or making sure that any arrangements that are made are followed through. Good communication is the key. If communication breaks down the repercussions for the individual can be disastrous.

Communication

Tim was the gentleman who had found it difficult to make friends in his hometown. Eventually, he found friendship after he joined a folk club in another community (see page 36). These people were genuine friends and cared for him in a way that you don't often find. However, several years after these friendships had been established, the group became concerned as they had not seen him for quite a few weeks. Club members had bought him Christmas presents and were quite worried about his wellbeing.

Some members made enquiries and it transpired that there had been a change in staff and his flat mate had left and new workers had taken over. Information with regard to the club had not been written down and Tim himself could not tell staff the



time it started, or where it was. He just knew he went on a Tuesday night. His friend's phone numbers had been kept in the flat mate's diary and now staff were no longer able to contact him. The service provider and staff learned a very valuable lesson from this incident. Now, Tim has his own diary and staff support him to update it regularly. It is also now part of staff induction to ensure that all information is recorded and updated regularly to ensure that this situation does not happen to Tim and others again.

Things to consider

Sustaining relationships can be hard work and needs continual attention to keep the relationship alive. Both parties need to be responsive, but sometimes some people are just better at it than others. One person can't carry the whole relationship by themselves. It's a two-way partnership.

Friends don't judge each other. They might not always agree with what their friends might say or do but they still stand by each other.

Honest communication is also another part of friendship. Friends rely on each other for advice, a shoulder to cry on or just someone to talk to. Friends keep each other's personal information to themselves and don't share it with others. Support staff should be very aware of the importance of privacy and should support individuals to do likewise.

We sustain relationships by many means including:

- Texting
- Phone calls
- Cards
- E-cards (some are free)
- Invitations to dinner, coffee
- Starting a tradition e.g. every last Saturday of the month going for a bar lunch
- Having a party
- Looking at 'what's on' that you are both interested in and offering to organise
- Facebook



- Offering help when needed e.g. let dog out if out for the day.
- By having a strong reason to sustain the relationship – maybe a hobby or interest in common
- Being reliable, on time and cancelling, if necessary, as well in advance as possible
- Remembering what makes the other person laugh
- Celebrating big and small triumphs
- Staying abreast of important milestones
- Giving something that is ‘handmade’

This list is not exhaustive but may give you a few ideas.

As a support worker you always need to be assessing how well a friendship is maturing. We constantly need to be aware of how well the relationship is progressing and that the relationship is genuinely with the individual and not with you. If you are confident that the friendship is genuine you can start to withdraw your support gradually to start with, making sure that both parties are comfortable with this. You could start by suggesting going for some shopping while they are finishing their coffee. If things go well you can progress from there but don't withdraw too quickly as you and your friend may have misread the situation.

For a friendship to be sustainable it needs to be fun and enjoyable for both parties. If it is a chore to meet up, then the friendship is unlikely to last.

We all have busy lives and sometimes making time to meet up can be an issue. In this instance you could look for ways to meet up which do not put either of you out of your routine too much. For instance, if a friend goes food shopping on a Thursday night, you could meet in the café for a coffee before shopping together. This way you can catch up on news and your friend can still get on with her shopping.



Things to watch out for:

- Many people are more than willing to form a friendship but they do not want to end up in the role of 'personal assistant', so be very aware of this. Support workers may still be needed for personal care issues or transport.
- Make sure that the individual is not making too many demands on the friendship.
- Remember the individual might confuse what friendship is and confuse it with a relationship.
- Some individuals might pay a lot of attention to their friend's husband or wife which could lead to problems and uncomfortable situations. It could even lead to the end of the friendship.
- People may not have had many friends before and may need emotional as well as physical support to maintain the friendship.
- We need to be aware of the possible potential for abuse to be present in the relationship. Steps need to be taken to assess the relationship regularly without over protection or cosseting.
- Once the relationship has been established for a while we need to continue to encourage and support the relationship.
- As a support worker you have to continually be promoting the gifts and strengths of the individual, even after relationships have been established.
- Keep an eye out for possible barriers - e.g. have a few meetings been cancelled? Has someone been offended or has something happened that you don't know about? Take time to get the two friends to talk things through and explore any issues there might be lurking in the background. Help the person you support to look at things from other people's point of view.



7. Getting Creative

It has been my experience over the last 25 years that, in order to truly understand who a person is and what makes them tick, you have to step into their shoes and walk around in them for a while.

Some of my best work and success has been where I have really been able to connect with an individual and understand, from their perspective, what they wanted in their lives. Walking around in their shoes was fun!

How did I do this?

I had to work out what was important for the individual from their perspective. Not what their family, health professionals or staff ‘thought’ was important. For example, from other people’s perspectives it might be the most important thing for the individual to be on the correct medication or for them to be safe. Yes, of course these things are very important, but they might not be important to the individual.

I had to find a creative way of engaging with them in order to meet their outcomes. It didn’t matter how silly or outrageous the things people were interested in. I had to look closely at textures, sights, sounds, colours, rituals, along with favourite people and places. I had to ask the ‘Why?’ question to rituals that had been taking place for years, so that I could get a clue as to what stimulated the person and their imagination.

Geoff’s story - who’s Who?

A few years ago I was asked by a locality manager to work with Geoff and his parents. For quite some time Geoff had been telling staff that he wanted to move into his own house. His parents were emphatic that he was not leaving the family home. The manager had a duty to listen to Geoff and asked me if I would do some planning with the family.



To begin with the family was quite tense and resistant to the planning meeting but after we started talking to Geoff about things he liked to do and about his family, the tension in the room subsided.

It transpired that Geoff's main interest was the *Dr Who* TV series. When Geoff talked about *Dr Who* he became very excited, animated, talkative and enthusiastic, which was a very different Geoff to the one I had met on previous occasions. Before, Geoff had been very quiet and unresponsive.

I decided to concentrate on Geoff's passion for *Dr Who*, and as a group, we began to list all the things Geoff could become involved with that was associated with *Dr Who*. Geoff's mother and father relaxed and began contributing with ease during the planning process.

We found clubs: exhibitions, memorabilia for sale and a member of staff who was also a *Dr Who* fan and was happy to give us more ideas we could draw on. As we gathered more and more information I wondered if Geoff would like his own Tardis? I knew the answer! I tentatively put the question to the group and was surprised at the family's response. They thought that it was a great idea.

This led to several questions though: "How would we do it, where would we put it, where would we get the money from and who could help us?"

Geoff's dad told me that he had the perfect place for the Tardis. They had two garden sheds built apart with a space in the middle. He thought that we could use the ends of the two sheds as the sides of the Tardis, so we would *only* need a back, front and a roof! Quite easy really! Geoff's mum came up with the idea of putting an advert on the local radio asking for help to build the Tardis for her son. Geoff was ecstatic; I was in a daze as things were moving so quickly. They were so enthusiastic.

Mum got on the phone right away to the local radio station who was interested in the project. They asked local builders etc. to donate anything they could. A member of staff's husband was a joiner and offered to help us out. Before we knew it we had wood and paint coming out of our ears. The member of staff, who offered to help, made suggestions about the shape and design of the Tardis, inside and out. He also sourced memorabilia as well as donating some of his own collection.



The Tardis was taking shape and I wondered if we could take things a step further? Would it be possible to have Tardis sound effects and lights? I contacted the local college and asked if any students could help us in our quest. They said that they would be delighted to help.

When the Tardis was built (it didn't look anything like *Dr Who's* Tardis, but it was Geoff's take on it, it was big enough to have a table, chairs and a lounge in it. Geoff had sound effects and memorabilia surrounding him. He was very happy as he had been involved in the whole process.

Since the Tardis has been built Geoff has never asked to move from the family home. I suspect that what he wanted was his own space, away from the noisy activity of a busy family home. Not only is Geoff happier, his family also enjoyed the planning process. Now, if they have to plan with Geoff again, they will be less anxious as they have already had a positive experience.

This piece of work involved community capacity building (using connections in our community – college, builder's merchants) which in turn has had many benefits for Geoff personally. Geoff has made friends and has a new Dr Who buddy, who will take him to conventions. He has worked with family on his own project and now has a place of his own, where he can chill out or can invite friends.

Tina's story - a horror story

One of the most interesting challenges I have had was when I was working with a lady named Tina. Tina had spent many years in a locked ward in a large hospital. Her reputation was fearsome!

Tina move out of the hospital and into a home of her own. She was supported by a progressive service provider and an excellent staff team (some were members of her family).

Tina's move from hospital had gone exceptionally well considering the dramatic change in her environment. The team were working together using a consistent approach and Tina's disturbed episodes became much more manageable. The challenge for the team was to find out what Tina liked to do. So far they had only found a few things that Tina seemed to enjoy, but they couldn't really be sure.



To add to the difficulty, Tina was on 3-to-1 support for some types of outings and 2-to-1 for others. She would not tolerate a staff change over as she liked to have 1-to-1 attention. Staff had to phone for a hand over at the end of a shift.

The organisation asked for my support to work with Tina and her team to find out who the real Tina was!

The first challenge was trying to get Tina to be comfortable in our meetings. There were various things which had to be considered in order to keep ourselves and Tina safe. One particular point we had to observe was consistency. Whatever Tina did to distract us, I had to carry on regardless of what was happening. Two identified members of staff would deal with the situation. I trusted the staff implicitly which was just as well as at one meeting the staff and Tina were wrestling under the table. Tina was pulling their hair and so on. I carried on as per the policy and a short time later the three of them emerged from under the table and sat as if nothing had happened.

On another occasion the area manager let her guard down and sat just a little too close to Tina, and she ended up with a burst lip (the manager admitted it was her fault as she was invading Tina's space). Again, as before we carried on with the meeting as the manager tried to ignore the blood pouring from her lip. Again, Tina settled and sat quietly for the remainder of the meeting. I must admit that we all found it hard not to react to Tina's outbursts, but the procedure worked. We had some strange meetings!

As Tina began to get used to our get-togethers she became more comfortable, and we were able to ask her to tell us what she was trying to say to us. Instead of reacting we tried to get her to stop and tell us what she wanted. This was a slow process but it began to work. Tina would now sit in our meetings and we could ask her to take control of the meetings. The staff team and I would arrive at the meeting and like in the big brother house, Tina chose who was evicted. Whoever was chosen had to leave the room including me! Thankfully, I wasn't chosen too often. This strategy worked and Tina began to trust that if we said we would do something, we would try our best to do it for her.

We found out that Tina liked horror movies (we had read in her notes that she had a fixation with death!) and contrary to what was in her notes she found it amusing and



funny and not at all morbid. At one meeting we surprised Tina by all wearing Dracula teeth. She found this great fun and started to ask “When was the next meeting?”; Tina was becoming more and more involved and taking charge of her meetings.

I was getting to know Tina much better and realised what a fun character she was with a wicked sense of humour, very much like my own. She would sit with staff and look through catalogues at the men’s underpants page and point and giggle. (Can I point out I have not done this myself for some time). She would laugh if anyone fell over and so on. At one particular meeting Tina was getting irritated and I knew where this frustration could lead. So I said to her “Show me what you want!” She immediately got down on the floor and crossed her arms over her chest. I said “I know what you want you want to be Dracula”. Tina got so excited. Staff had never seen her like this. So we had to make it happen. We decided as it was coming up to Halloween this would be a great opportunity to have a party, but how did we do that when Tina could only tolerate being with one person at a time? At our next meeting we asked Tina if she was having a party who she would like to invite. Going through books Tina pointed to the Scream, a werewolf, a man with an axe through his head, vampires and so on. She loved to be frightened. Tina also pointed to Dracula in his coffin again.

At Halloween the staff dressed up the house with huge spiders and cobwebs and I managed to source two cardboard coffins (don’t ask). We had the usual Halloween things to eat and at 10 minute intervals staff came to the door dressed as all the characters she had chosen. She loved opening the door and not knowing who was behind the mask. The person came in for five minutes and then left. This worked well as all the attention was still on herself but included other people for a short period of time. She also had her wish of lying like Dracula in a coffin with her favourite member of staff lying beside her in another one.

We continued to meet and over a period of time Tina’s anxiety levels reduced quite considerably as staff could stop her and get her to tell them what she wanted. She still had outbursts, but they were not nearly as bad. Support was reduced to a 1-to-1 basis inside the house.

We took the horror theme a stage further and stayed a night in a Cathedral. We had scary music, food which looked awful and cakes like chopped up fingers. Drinks were either bright green or blood red. Tina had a ball. The final pièce de résistance was when Tina was handed a key and was asked to find out which door it opened. She had



a torch and searched through the whole room. There were many doors to open and Tina's excitement grew and grew with each one she tried. Finally she opened the door and her cousin jumped out. It was a huge success.

After this party we organised a Birthday party for Tina, based on the TV programme, *Happy Days* with the Fonz. I knew that Tina liked motor bikes so I gave her a pair of my leather bikers' trousers. She was delighted. We invited friends to the garden party and they had to dress in the Fonz theme. Tina could cope with people in the garden much better than in the house so people could stay for a little while. The final surprise involved a member of staff arriving on his motor bike in a kilt with her cousin on the back, holding Tina's birthday cake. Later Tina got on the bike and was driven around the garden. She had a fantastic time and had come quite a long way.

From this point on I felt that the staff knew how to communicate with Tina and they had found out that she wanted fun in her life. Tina's type of fun! On my last session Tina came in to the meeting with staff and she was holding a picture. The staff said that Tina wanted to show me something. Tina came over to me with a picture of three little Chinese boys covered in paint and pointed to the picture. I asked her "Is this what you want to do?" she nodded. The staff were now charged with working out how and where they could get Tina a chance to roll around in paint!

Tina had learned that she could trust us to listen to her and that we would do our best to make things happen for her.

Grace's story - in the pink

Another interesting lady I worked with was Grace. Grace was on the Autistic spectrum and had a similar reputation to Tina. She had attended a day centre for the last 10 years. Staff at the centre had become demoralised and burnt out due to the intensity of support and concentration needed to keep the general public and themselves safe. Grace was very unpredictable and her mood could change in seconds. Grace's mother was also under the same pressure and life with Grace could be, at times, traumatic.

John, the manager of the centre, asked me to work with Grace, her family and the staff supporting her at the centre.



The atmosphere at the first session with the staff was apathetic and they quite clearly did not want to engage with me. When we discussed the fact that if possible I would like Grace to take part in the sessions however short the time, I was told that there was no way she would be able to join in.

We continued talking about the things that Grace enjoyed doing and staff told me that one of the things she did every morning was a jigsaw. By doing the jigsaw staff could assess what kind of mood Grace was in. If she did the jigsaw smoothly, she was in a good mood, but if she crammed the pieces in to place it would most certainly not be a good day for Grace.

I thought that this was an interesting way of judging Grace's mood and, as it was something she did everyday with the same jigsaw, asked if Grace could do her jigsaw at the beginning of our meeting. The staff thought this might work if Grace sat at the back of the room and didn't have to make eye contact with anyone. Grace could then leave at any time she wanted, but at least she would have been there. We tried this approach and it proved to be successful and Grace continued to attend the meetings. As time went on Grace became more interested in our meetings and staff moved her table further and further towards our circle. Grace eventually joined us and sat with us for varying lengths of time.

I learned from staff and Grace's mother that she adored Christmas and all the decorations. "Grace would love it to be Christmas everyday" said Grace's mother. Staff also told me that Grace loved the colour pink, loved shopping, surprises and anything to do with hair accessories.

As Christmas was the most thrilling and exciting thing for Grace I began to look at how we could have 'a little bit of Christmas every day' for Grace.

I came up with the idea of Grace making her own Christmas tree which could be dressed over the year by making a decoration every day. The tree would be painted pink. I asked the staff to take Grace out to a wood and look for suitable branches for her tree. They could then come back and put the tree in a pot of cement and Grace could paint it. Grace was to be as involved as much as she wished.

Staff reported that they had never seen her so focussed and attentive. Grace loved being in the wood with the staff and choosing her tree. She spent ages painting it



pink and took great pride in showing it off. During this time Grace did not get upset - something which would normally happen several times a day. The next week they started to make a decoration, in pink of course and Grace added it to her tree. This continued and Grace looked forward to making her decorations.

Staff also said that Grace would get upset when she was in the cooking class although she did appear to enjoy it sometimes. I suggested we dye her 'whites' pink and then make food which she could colour pink. This worked again and the cookery class became much more fun for Grace.

Staff also told me that Grace would go into someone's bag every day and take their keys out and keep them till the end of the day. When I asked staff why they thought she did this they said "She has always done it". On further exploration staff thought that maybe it was because she wanted that member of staff to be with her that day and she knew that they couldn't leave without the car keys. Grace did seem to pick her favourite staff's keys more often than others. Was Grace choosing who she wanted to be with that day or was it a game? We decided that it was not a game as she always gave the keys back at the end of the night. Maybe she was just saying she liked that person that day?

As I thought more and more about what Grace was telling us I was reminded of the jigsaw. Grace had been doing the same jigsaw every day for years. If staff were using the jigsaw to evaluate what kind of mood Grace was in, perhaps we could use the jigsaws to reduce Grace's agitation.

I asked who Grace's favourite members of staff were and with their permission I took photographs of them. I then got them made up into inexpensive jigsaws. My idea was to present Grace with a surprise every day. She would not know who was going to appear until she did her jigsaw every morning.

It turned out that Grace loved it and this meant that we could use the jigsaw to let her know who would be working with her on that day. It could also tie in with the staff member's keys: Grace could hold the key worker's keys for the day which matched the jigsaw.



As the sessions continued I could feel staff morale lifting. Grace's mood swings were becoming less (we knew that we would never completely change this and Grace was still on 3-to-1 support) and staff were seeing Grace in a more positive light.

Staff were enjoying being with Grace.

Grace's mother had also seen a big improvement in Grace's demeanour. Home life was much happier and settled. Grace presented her mother with a pink Christmas tree for the house and her mother was over the moon. It was the first thing that Grace had ever given her. She would usually keep things to herself.

Things were going well and staff were motivated enough that I thought we could start to try and get Grace linked to her community. Grace loved anything to do with hair and hair accessories. She had beautiful long thick blond hair. I remembered that I had asked the staff to complete the activities and connections exercise (see Figure 1) and that a staff member's sister owned a hairdressers shop. I wondered if her sister would help us. Grace's mother had always done her hair herself as going into a hairdresser could be problematic for Grace. Jane the hairdresser was willing to get to know Grace. As Jane's sister was a member of staff it was easier for her to get to know Grace. Grace started visiting Jane in the shop when it was closed. Jane built up trust with Grace and Jane was eventually allowed to brush and wash Grace's hair. Jane progressed to putting Grace's hair up into different styles with all sorts of fashion accessories. Things went well enough for Grace to eventually visit the shop while it was open for a cup of coffee. Two staff could now accompany Grace and she was coping well. Staff had new ways of working and thinking. They could now "walk in Grace's shoes".

The team were doing so well with Grace and were motivated to continue to support Grace to have a happy, fun filled life. I felt that they no longer needed my support.

At the last meeting we made an action plan for the future. The main thing staff wanted for Grace was that she could experience having a girlie night away from home. Grace had never been on a holiday without her family. These trips were not usually very successful and eventually the family gave up on holidays as it stressed everybody out. So, this would be a challenge but they seemed up for it. I left them with their plan.



About a month later I got a phone call from a member of Grace's team. She was ecstatic and couldn't wait to tell me the good news. Yet again a member of staff had suggested that Grace could use her caravan which was not far from Grace's home. She was willing to let Grace stay overnight along with members of staff. The caravan was close enough to get home quickly if needed. The staff were up for it but was mum? Grace's mum was apprehensive but trusted the team. She agreed to be on call should she be needed.

Grace loved her overnight stay. She didn't get anxious and loved every minute of the experience. Grace went off to her room quite contented and kissed everyone good night. In the morning staff woke to find Grace in bed with one of them, dressed in one of their night shirts. They think she wanted to be one of the girls.

Grace's mother was in tears when she came home. Staff had planned, well in advance and was prepared to take calculated risks. Grace was well on her way to experiencing new and exciting things in her life.

Remember to be creative, listen to what gives people a 'buzz', and together, let your imagination run riot!



8. Facing the challenges

Supporting individuals with learning disabilities to develop friendships and venture into the community can be quite a challenging task. Many people in society have different views and values about life and how people should or should not live. As a support worker, you might face negative and discriminatory attitudes towards the dreams and hopes of the person you support.

Assisting people to lead the life they choose is the role that the support worker embraces. However, carrying out this role can be met with scepticism, negativity and prejudice on many different levels. Some people's negativity stems from fear for their loved one, and fear of the unknown. Working towards a change in attitude can be achieved if small steps are taken: one at a time gradually chipping away at their fears. Change doesn't happen overnight, so don't get disheartened.

Challenge 1 - "They have us!"

Sometimes the benefits of being part of the community are not recognised by a family and it is felt that being part of the family is all that anyone could need. Friendships outwith the family circle are deemed unnecessary. Often individuals struggle to make the family understand how isolated they can feel with no friends of their own. Most of us need friends of our own, who we can share new experiences with and thoughts and feelings that we could not dream of sharing with family.

Challenge 2 - "Dreams can't come true!"

Often family and friends can be quite dismissive of people's dreams due to their disability. We all have dreams of things we would love to try or do. For people with disabilities it might be necessary to plan a little more creatively in order for them to succeed and to achieve their dreams. However, most barriers and obstacles can be overcome, leading us nearer to the dream.



In a workshop I ran a year or two ago, I asked people to write down their dreams. Out of 27 people in the room we managed to make a connection for 19, bringing them closer to their dream. One woman wanted to learn sign language - a person in the group was deaf and offered to teach her. A gentleman wanted to learn to play the piano – we had a piano teacher in the group and so on. My colleague who was running the group taught the bodhran and I had no idea. I have been trying to find a teacher for years! It is all out there in the community, just ask!

Challenge 3 - “You’re setting her up to fail!”

At times people might imply that you are setting people up to fail. In such cases, it is essential that you have evidence of the person’s ambitions and then plan for as many eventualities as possible in order to achieve the best possible outcome. For example assess any risks and visit the venue on your own first to check things out. Don’t try to achieve too much too quickly; instead increase your chances of success by starting small. Once they have joined something or made a connection, film or take photographs of them enjoying themselves so the evidence speaks for itself.

Challenge 4 - Stay focused

Keeping the focus person at the centre of the planning process can be a constant struggle. Sometimes other people have their own agenda and fail to listen to the focus person. There are several ways of dealing with this situation.

These might include:

- Getting the group to set ground rules for planning meetings – this includes sticking to the focus person’s agenda.
- Constantly refer back to the focus person and check things out with them. This gives a clear message that they are in charge. Use body language to make them the centre of attention. Position yourself and others facing towards the focus person.



- If possible arrange the meeting room so that the focus person is at the top of the table and everyone is facing them. When out for a meal make the focus person the centre of attention by sitting them in the middle of any group, not at the end of a row.
- Get the focus person to video what they want to say before any meeting so that they don't get flustered or intimidated. They then get to say what they want. Care must be taken here so that you are not seen to be putting words into the person's mouth. Don't use leading questions etc.
- Use phrases like "What do you think Mary?" to bring the person back into focus.

Challenge 5 - Lack of enthusiasm

In certain circumstances family and friends may not wish to participate in any aspect of the individual's life. They may also have a negative attitude towards the individual. This is quite a difficult situation to deal with as you are immediately faced with negativity.

In the first instance try to get the family to participate by emphasising the importance of their input and how important their knowledge is.

If they do agree to have an input, explain that it must be positive things that you are working on first and that you will deal with overcoming barriers later. I have found that this usually works and I also remind them of this as we go through the meeting.

If family and friends do not wish to participate you then have to work with other people who know the focus person e.g. neighbours or a social worker. You are better working with a few positive people than scores of people with a negative attitude, as this will ultimately have an impact on the person you support.

Challenge 6 - Keeping people safe

This is always a fear for families and I can understand that their concern is only out of love for their loved one. However, people have to have a life! Look at achievable things to tackle first which are easier for families to get their heads around.



For example, If the ultimate aim is to get someone to travel independently, then suggest using a taxi together with them first. Use it regularly, get the same driver if possible and one who is known to social work and has had safety checks carried out. Set up an account so that in the future there is not a problem with the person handling cash. Get the individual a phone with pre-dial numbers and start getting them acquainted with it.

Consider other types of assistive technology to make both parties feel more secure and safer e.g. a GPS watch. Let families see that you are considering safety and planning ahead for possible problems, then they are more likely to come around to even considering small steps to new adventures.

Recognise that you know that it must be difficult and scary for them, but get them to think of the benefits for their son or daughter in the future. They will be proud that they can be independent and it will also free up some time for mum and dad!

Challenge 7 - No vision for the future

Many families struggle with thinking about the future. They often have difficulty getting past going from day to day activities and at times just filling in time seems okay. We can all fall into the trap of not thinking about the bigger picture, that is having a life: with a future, friends, employment etc. Many people end up doing course after course and never get to use the skills that they have learned, either in the home or in employment.

Sometimes it transpires that the individual is not really interested in a particular activity but it is the only thing that people have sourced for them. Support staff must be constantly supporting families and personal assistants to think about the future and working towards a happy, full and meaningful life with all that it entails.

Challenge 8 - “We’ve tried it all before”

For many families they feel that this is a fact and that they have exhausted every avenue already. They feel that nobody has managed to come up with any positive results so far. It is understandable that families get fed up attending meeting after



meeting when, in their eyes, they have not seen a result. Why should they believe in you?

In this respect you have to recognise that this might have been the case in the past but you may have a different approach from the other people involved before. It is often the case that the individual themselves might be in a better place now and, it might just be the right time to make things happen for them. They may have matured or circumstances might have changed for the better. Ask to give it a try even for a short time.

Challenge 9 - Prejudice and discrimination

If you work with people with learning disabilities you will come across prejudice and discrimination throughout your career. It can manifest itself in many forms from people discriminating about one's sexual orientation to their learning difficulty or just the team they support.

You are the individual's advocate and at times you must make the decision either to fight a particular battle with them or just to let some go! It depends on the situation. On one particular occasion I have been involved with a family who rejected their daughter, who has a learning difficulty, because she 'came out' and told the family that she was gay. In this instance the rejection and mental torture that the individual was going through from her family necessitated that staff had to support this lady through a very emotionally difficult period.

Challenge 10 - Lack of sexuality

“Sexuality, people with learning disabilities don't have any.”

This is a very common concept that the general public and many personal assistants have of people with learning disabilities. It must be challenged.



Challenge 11 - Cultural differences

When trying to connect people to the community you must be aware of cultural differences between different groups. Some cultures do not see women as having the same independence as men, or they might have different religious views from that of our own e.g. some cultures might disapprove of frequenting venues which sell alcohol. When connecting to the community we must respect these views and work within these parameters.

Challenge 12 - The end of friendship

This is a concern for many families. They fear that their son or daughter will get hurt if the friendship falls apart. The fact of the matter is that, unfortunately, this is life and we all go through pain at some point in our lives. When this happens we need to have people to support us to get through it. Just remember the saying:

“Better to have lived and loved than never to have loved at all.”

Challenge 13 - A different agenda

Sometimes unwittingly, people will put their own needs before that of the individual they care for. This can happen very easily particularly if a marriage has broken down or there have been other family disputes. This situation needs to be handled with care and, in this respect, it is essential to make it clear that the individual you are supporting has their own needs which have nothing to do with other people's agendas. If you are trying to support an individual under these circumstances, it might be useful to meet people separately to work through the individual's plan and get their agreement so that, at future meetings, the focus stays on the outcomes for the individual. Keep personal disputes out of any meetings.

Now that we have looked at some of the possible challenges that might lie ahead for you, I hope that you will feel better prepared for the future! But don't worry; you may never encounter any of these situations.



Conclusion

On my journey to better understand and to make a real difference in the lives of people with learning difficulties, and in particular those with complex behaviours, I believe there have been significant changes in attitudes in some areas; as we work towards supporting individuals to become citizens who are an active part of the community. People now have greater access to housing of their choice than ever before and employment for people with disabilities is much higher on the agenda.

However, when I look at how people with learning disabilities are viewed, we still appear to have far too low expectations for them. We seem to have come to a point where 'good' is, more often than not, 'good enough'. We need to change this approach to one which expects people to 'be all they can be'. We need to raise our expectations for people with learning difficulties and this can't be done without creativity and attention.

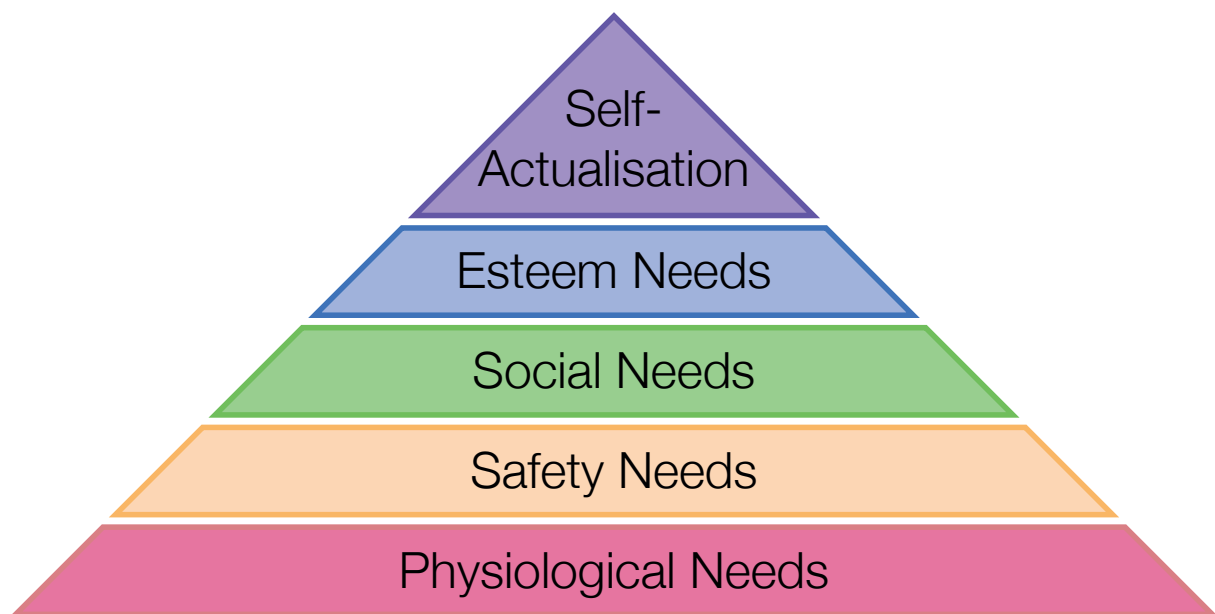


FIGURE 2. MASLOW'S HIERARCHY OF NEEDS



The psychologist Abraham Maslow showed that after our needs for safety have been met, the third level of human need is to have a feeling of belonging. His belief was that humans need to feel accepted and feel a sense of belonging, no matter how large or small the group they are involved in (see Figure 2).

Many groups can help us feel like we belong: co-workers, religious groups, clubs, professional organisations, sports teams, gangs or small groups including, family, intimate partners, or colleagues. As humans we need to love and be loved, both sexually and non-sexually, by others.

Our need to belong and feel loved is so strong that if we are denied it, it can lead to clinical depression or social anxiety. This need for belonging may overcome physiological and security needs depending on how strong peer pressure is.

I am sure that we can all identify people we know who are in this category. I have worked with many people with and without learning difficulties who are lonely and isolated and crave the feeling of belonging and being loved. We can also no longer put off thinking about relationships and the positive impact it can have on peoples' lives. People with disabilities need to be seen as sexual, loving, caring individuals who have the same needs as you or I.

I hope this guide helps you to see how everyone can belong. It may take work, thoughtfulness and creativity but we all do belong, and we must not leave anyone without love.



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Friendship © Kay Mills 2015

Figure 1 © Kay Mills

Figure 2 © Abraham Maslow

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Information

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Kay has worked with people with learning difficulties, autism and mental health problems for over 20 years. She is best known for her innovative work with individuals: helping people form new relationships, find work and get stuck into community life. Kay is passionate about supporting people to be respected and have a fulfilling and fun filled life.

Having worked at a senior level in both residential and personalised support services in the West of Scotland, Kay founded **LEAF** (Life, Employment and Friends) in 2001. Her work has particularly focused on supporting people who have become marginalised to maximise their own potential. She specialises in working with individuals, families and staff who are stuck or who have run out of ideas. She often also works as a mediator between services and individuals.

Kay has also supported wider system change, working particularly closely with North Lanarkshire Council - one of the most innovative Scottish local authorities. Kay has helped social workers and managers to learn new skills and focus on capacity-building within their local communities. Kay has expertise in person-centred approaches, community mapping and bridge-building, overcoming communication difficulties, sexuality and family-centred work. She is well known for her creativity and positivity and she believes like Charlie Chaplin that “A day without laughter is a day wasted”.

Find out more about Kay’s work by watching a selection of films [here](#). Please get in touch with Kay if you think she could help you or someone you know.

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Open Future Learning

Open Future Learning is a multi-media platform for online learning. Its founder Ben Drew has filmed many of the leading thinkers and practitioners working with people with disabilities, and his innovative system for learning provides inspiration and practical advice.

Open Future Learning has just published a new module developed with the author Kay Mills to explore the ideas set out in this paper. Visit their website for more information about the **Building Friendships and Community** module.

Visit: www.openfuturelearning.org

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