An Honorable Event - Marianne shares experiences whilst networking at No. 10

At the end of February Samantha Cameron held a Reception at No. 10 Downing Street for some of the staff of Scope, representatives of associated groups, such as Us in a Bus, funders and some of the people who, over the years, have come to Scope for help.

And we were honoured that our very own Marianne Hecker, one of our Trustees and co-founder of Us in a Bus, was invited to attend.

“It was such a fascinating experience and a privilege to be there. I loved going through that often seen black number 10 door, walking up the staircase to the Reception and passing all those ex-Prime Ministers’ portraits and photographs. And the refreshments were delicious!” she said after the event.

Us in a Bus was set up by the Spastics Society, now Scope, 25 years ago and, although we became an independent Charity three years later, Marianne has kept the relationship with Scope alive. The Reception gave Marianne the opportunity to chat to a wide range of people and share experiences with them. This was also the ‘outing’ for our brand new business cards and Marianne was pleased to give them out to people who were interested in our Service.

Samantha Cameron led the speeches with a warm welcome to everyone and was followed by a parent whose contact with Scope, at a very difficult stage in her son’s life, had helped to save her sanity. The final speech was by the Chair of Scope, bringing this wonderful event to a close.
MESSAGE FROM THE CHIEF EXECUTIVE

“We are extremely proud that we are now in our 25th year of providing unique services to a wide range of people who have profound learning disabilities and complex needs.”

There are so many people who have supported Us in a Bus over the years, who we owe a huge thanks to. We depend entirely upon income generated from providing sessions with clients, training and consultancy fees, fundraising and the generosity of individuals and grant giving organisations to continue to deliver our work. So we are delighted that this year we will be holding an extra special 25th Anniversary Summer Party on Saturday 11 July including as many of them as possible.

As we began this year there was a real buzz amongst the team and our trustees as we started to arrange a number of special events to celebrate the innovative ways in which we have changed our approach and services over the last 25 years.

We are planning a very exciting sensory event on 18 June for as many of the people we support as possible.

The organizing team are working on the final details now, but I can tell you that the event will reflect some of the vibrant colours of our new logo and encompass elements of sound, smell and touch to provide a truly unique experience.

And finally, we want to share the things we have learned more widely to ensure that all those supporting people who find communication challenging appreciate the impact that meaningful connections have on self-confidence, self-esteem, mental health and emotional well-being.

On Wednesday 2 December we will do this at our Conference to be held at the Reigate Manor Hotel. As well as some thought-provoking presentations, there will be a number of Master Classes for people to sign up to where they can learn more and take part in discussions. Invitations will be sent out during August, but you can also check out our website for more information – www.usinabus.org.uk.”
Time to say Goodbye ...... by Julia Hancock, Chair of Trustees

“Many years ago I worked in a large hospital for people with learning disabilities. It could be a big, confusing place and little attempt was made to explain to service users what was happening. But there were a lot of parties! There were parties when a carer or member of staff was leaving and people were happy. There were parties after a church service when people were sad. But sometimes people just disappeared with no explanation. Many residents showed signs of depression and bereavement for some years after losing a close friend, having been denied the opportunity to attend their funeral or to grieve in any way.

Over the years I have worked with families, carers and therapists to improve this situation and to talk about things which may be difficult – such as death, people moving away or an elderly parent being unable to visit.

When someone died, particularly if it was a member of the household, there was a sadness, an uncomfortable atmosphere in the home, so it is important to give people the news as soon as possible. We cannot be sure how much an individual understands, or whether they can relate to photographs, so I would always use several props, backed up with simple words and phrases, “Mary has died”; “We won’t see her again”; “We feel sad”. For example, when telling service users that their friend, with whom they lived, had died we would use the individual’s empty wheelchair, a hat that they always wore, or use a sound that we associated with the person who had died. If it seemed appropriate we would sing a goodbye song. We would pass round a photograph, all the time acknowledging peoples’ reactions and acting accordingly. It was rare for someone to react immediately by crying or openly seeming upset. If they did, it may have been in response to the sad atmosphere or uncertainty.

Wherever possible people should attend the funeral of a family member or friend. We should not just avoid a situation in case the individual becomes upset as it is an important part of the grieving process, but we can attempt to help their understanding and be sensitive to a person’s mood.

Again we would use photographs, objects and music familiar to the person. Funerals are to say farewell and this can be enhanced by the release of helium balloons outside the church or crematorium and saying goodbye as they drift away.

I have been with people who have responded to the death of a close person in very different ways. One lady took me to the bedroom of the person who had died every day for 15 days so we could check that she was not there. On the 16th day she decided not to come with me - she didn’t need to look any more. It was fortunate that the home staff didn’t clear the deceased’s room until after that point. Another person didn’t appear to react at all to the news that his mother, who visited him every week, had died. He showed no response to the sadness of other family members, at the funeral or to his mother’s absence. Several weeks later he went off his food, became withdrawn and agitated with no other obvious cause. We talked about his mother, made up a memory box and supported him throughout. Everyone reacts differently, so we have to watch out for any change in behaviour, mood or physically.

Care homes these days are much more aware of the emotional well-being of their people and have a policy on how to support them through bereavement, responding to their needs sensitively and respectfully. It’s always important to acknowledge a loss, to speak about a carer who is leaving or a friend who may be moving away from the area and to recognise that an individual may experience similar emotions to when someone has died.”

The staff at Us in a Bus feel a close connection to the people they support and they take time at every Staff Meeting to remember any who have unfortunately passed away. This is done fondly with love, remembering the good times and the person’s many accomplishments. Us in a Bus has also developed a set of guidelines to help their staff support someone following a bereavement and there are many other resources available to help.
MAKING CONTACT BY USING TOUCH

At Us in a Bus, using physical contact with the people that use our service is an integral part of our work. However using touch with people that are vulnerable can be a minefield. It can be open to misinterpretation and peoples’ histories, as well as their disabilities, can add complex issues to how touch is perceived.

Us in a Bus has comprehensive ‘Guidelines For Using Touch’ to safeguard the people receiving our service as well as our practitioners. These guidelines are readily available for anyone wishing to see them. In this article Jan Murrells, Senior Practitioner, explores how we use touch at Us in a Bus and why we feel it is so important.

“Touch is a primal form of communication. Alongside smell it is the earliest form of communication that we experience as babies. The first contact we have with our Mothers is to be held by them and it is well documented how important skin to skin contact is as this stage. We recognise the scent of our Mothers before we are even able to see them properly.

With this in mind we can begin to understand why, for people with little or no intentional communication, it can be vital to building relationships and open up the possibilities of communication. Being held by our caregivers provides comfort, security and warmth, making it possible for us to feel loved and all the other building blocks for positive feelings of self worth.

Touch also reinforces other forms of communication. In our daily lives as adults we may not use touch as much as we did when we were children. Depending on our own personalities, relationships, personal boundaries and social environments, we use varying degrees of touch on a daily basis.

A lot of the time with friends and family, as well as in the work place, we don’t need to use touch at all. Our communication skills are well developed and on the whole we are able to communicate successfully using words without the need for any reinforcement.

For people with profound learning disabilities and complex needs, this is not the case. They are not able to use words or intentional gestures to communicate their wants and needs and they are often unable to interpret the meaning of our words and gestures, this is why at Us in a Bus we use Intensive Interaction.

Continued on page 5 ...
When we use Intensive Interaction we need to think about the whole person we are aiming to engage with and all of their senses. We need to make it as easy as possible for the individual to know we are trying to connect with them and learning their language.

Many people with profound learning disabilities and complex needs also have some degree of hearing or visual impairment - some are blind, some are profoundly deaf and some are both deaf and blind. We need to make sure they have heard that we are echoing their sounds, we need to make sure they can see we are mirroring their movements. They may not have any kind of visual or hearing impairment, but it may be difficult for them to understand what they are seeing or hearing.

By adding touch when we respond to a vocalisation we add another opportunity for the individual to feel heard: George says “yip, yip” and we respond with a “yip, yip” with two firm and quick squeezes to his shoulder. Instead of relying on the person just hearing our response they have two types of feedback to their communication. Joyce says “aiiiiiiiiaaaaa” we say “aiiiiiiiiaaaaa” back to her and rub the back of her hand as we say it, the same principle applies. Beth is rocking rhythmically in her chair, we want to join in with her, to start to let her notice that we are there with her and available for a connection. We rock in the same way she does. We might add some sound too, perhaps patting our own knees to make a sound and reinforce the rhythm. Once we’ve done that a few times, we might pat Beth’s knees in the same rhythm as well as keeping up the rocking.

These are just a few simple ways we use touch to add possibilities to communication and connection. As mentioned at the beginning of this article, there are many issues to consider and I’ve not been able to address them all in this short article. For example, we would not try making any type of touch before we’ve assessed an individual’s sensitivity to touch, based on their histories and possible hyper or hypo sensitivities.

We also use touch to address peoples’ need for proprioceptive reinforcement and this is a subject that that I will explore in greater depth in a future article in Linking Lives.”  

By Jan Murrells, Senior Practitioner

**INSPIRING WORDS**

The Inspiring Words we have chosen for this edition of Linking Lives come from the very inspirational South African leader, Nelson Mandela:

“I learned that courage was not the absence of fear, but the triumph over it.

The brave man is not he who does not feel afraid, but he who conquers that fear.”
2015 TRAINING OPPORTUNITIES

Janet Gurney, Chief Executive of Us in a Bus, offers two day-long Intensive Interaction Workshops. Places can be booked by calling Us in a Bus on 01737 764774 or emailing admin@usinabus.org.uk.

The first is an Introduction to Intensive Interaction and is for anyone who wishes to relate more closely with people who have profound learning disabilities, including family carers, residential and day services managers and staff teams, care managers and advocates.

Participants will have the opportunity to:
- Understand the principles and techniques of Intensive Interaction
- Explore how these principles can be used
- Be enabled to build more fulfilling, interactive and equal relationships with the people they support

2015 workshop dates still available are 21 July and 8 October

The second is a Next Steps workshop and is for anyone who has already attended Janet’s Introduction to Intensive Interaction workshop. During it you will reflect on your practice of Intensive Interaction and explore how to extend the connections you’ve built with people who have profound learning disabilities.

Participants will have the opportunity to:
- Use a reflective learning approach to explore their use of Intensive Interaction so far
- Share experiences and ‘trouble-shoot’ any challenges being faced in implementing Intensive Interaction
- Explore the core purpose of Intensive Interaction for individual service users
- Make plans to ensure the sustainability of Intensive Interaction in their workplace

2015 workshop date still available is 4 November

Conference to share 25 years of learning

The team at Us in a Bus will be sharing the things they have learnt during the last 25 years at a Conference to be held on Wednesday 2 December at the Reigate Manor Hotel.

Understanding more about the impact that meaningful connections have on the self-confidence, self-esteem, mental health and emotional well-being of people with profound learning disabilities will be at the heart of the Conference, so make sure to keep the date free. There will be more details about how to register for places at the Conference on www.usinabus.org.uk soon.
Meet the People behind Us in a Bus

In the first edition of 2015 we get to know a bit more about Nicky Bracey, an Interaction Practitioner at Us in a Bus ….

Q A How long have you worked for Us in a Bus?
I began working for Us in a Bus in January 2008. Initially I was employed to cover maternity leave, but I am pleased to say that I’m still here!

Q A What’s been your most memorable moment at Us in a Bus so far?
There have been many memorable moments, but they all illustrate the value of perseverance in our work. Continuing to be available and letting the people we work with know that we are there to interact with them when they are ready to do so on their terms, is a big part of our job. I couldn’t keep it to one, so here are my top three most memorable moments:

C was often very sleepy and I wasn’t always sure that he was aware of us and who we were for the first couple of years of working with him. Then one day he turned towards the guitar very obviously and with great effort and with a big smile on his face. These days he often turns and smiles as we greet him, and he reaches out for both the guitar and the keyboard as well as us.

When we first met B he spent a lot of time with his head down and his eyes closed and we began responding to very small movements which he made with his fingers. His mum told us that he used to vocalise but had stopped using his voice. Recently he seems to have rediscovered it! We have shared some joyful times with him where he has explored our keyboard extensively and used his deep melodious humming vocalisations to “sing” along for extended periods, with a contented look on his face.

R struggled with close proximity when we first met him, so we worked with him at a distance. Now the three of us share a sofa, often sat very closely together. Recently as we laughed together during a story telling session he reached out and gently placed a hand on each of my shoulders and made extended eye contact, a real moment of warm connection.

Q A What’s the best thing about your job?
The best thing is being part of a team of knowledgeable, passionate people who are privileged to meet and build warm relationships with so many interesting people.

Q A What’s been your biggest achievement in life so far?
It has to be giving birth to my two sons and, along with my husband Richard, providing a loving, secure base for them. It has been a pleasure to watch them grow and develop into the fantastic young men that they are today (I am of course biased!!)

Q A What do you like to do in your spare time?
I am a big football fan and as well as transporting and watching my sons when they play I am a passionate Woking F.C. fan. I also love to walk, read, spend time on a narrowboat, take part in my local village pantomime and play the saxophone.

Q A What’s your favourite food?
I like good homemade soups and Italian food.

Q A If you were stranded on a desert island what two things would you most like to have with you?
I would take a hammock and my guitar.
US IN A BUS IS RECRUITING!!

We’re looking to expand our team and are looking to recruit two Interaction Practitioners (one full and one part time role).

We are looking for people who can use their creativity and imagination to engage adults with profound learning disabilities and complex needs in interactive, sociable experiences. We would like them to know about Intensive Interaction and to be interested in the chance to use it to connect with people who find communication a challenge.

We are looking for two people who are self-motivated, energetic, flexible and looking for a job with responsibility to join our teams based out of Redhill and Guildford. A DBS check is required for these positions.

This is a great opportunity to join a dedicated, fun and supportive team who are daily making a difference to many people’s lives.

If you are interested, please email admin@usinabus.org.uk for a Job Description and Application Form.

Closing date for applications is 1 June with interviews proposed for 1 July and a potential start date of 1 August 2015.

Spot the Van Competition Winners

Congratulations to Lily and Kevin Smith who were the first to email Us in a Bus with the day, time and place they saw one of our newly re-branded vans!

Don’t forget to give us a wave when you next see us out and about.
A Rewarding and Fulfilling Opportunity

by Marilyn Anderson, Volunteer Marketing Assistant

“At the age of 55, after 39 years of service with BAE Systems in the Communications function, I was in the fortunate position to be able to take an early retirement package. But whilst it was good to have some time to do all the things I wanted to do, I wasn’t quite ready to retire fully so I set about looking for what to do with the next chapter of my life.

And I think ‘Lady Luck’ was shining down on me that day when I searched on the Charity Jobs website and found the advertisement for a part-time volunteer Marketing Assistant for Us in a Bus. With my previous experience in communications and marketing the job could easily have been written for me. So I applied and was delighted when I got the job!

That was a year and a half ago and I am so pleased to have been involved with Us in a Bus during a very busy time of re-branding the charity and all the activities that go along with that. I found it very enlightening going along to sessions to capture new imagery and video footage, although I did find the first time a bit scary, not quite knowing what to expect. I have a great deal of admiration for all the Interaction Practitioners and Sessional Workers who bring so much experience, care, dedication and love to each session they do.

Part of my role is putting together this Newsletter, Linking Lives, which is a lot of fun and which is hopefully helping to spread the word about the important work that the charity does and the huge difference the team are making daily to many people’s lives.

I am so pleased to have been able to volunteer with Us in a Bus and use my skills to make a difference to the charity. For me it has been an extremely rewarding and fulfilling experience and has also been lots of fun too! This year Us in a Bus is 25 years old and we are celebrating with a number of events during the year, which I am delighted to be involved in.

Us in a Bus relies on fundraising to provide the services it offers and they are currently looking for a part-time volunteer to help with their fundraising activities. So if you are reading this and have some time to give to a charity, I would most certainly recommend joining the team at Us in a Bus.”
Spotlight on Fundraising

Brighton Rocks!

The sun shone brightly on 12 April in Brighton for the 2015 Brighton Marathon. There seemed to be even more people on the streets cheering the runners on, who this year included, Rozie, Rachel, Aleks, Svetlana and Sergejs, all running to raise money for Us in a Bus and four of whom had never run a marathon before.

Rich, Rosie and Renée, from Us in a Bus, were waiting at the finish line to welcome them home! Unfortunately Rachel had to pull out after 17 miles due to a knee injury, but the other runners all finished and she helped us to congratulate them on their massive effort. Rozie also had an injury that had held back her training, but the smile she gave us when she crossed the line with her little sister was inspiring and very infectious!

Four of the runners all work together for Santander UK plc in their Corporate Team and have been training together and raising funds in the office. Svetlana finished in a time she was really pleased with and said afterwards “Taking on a marathon is a very difficult challenge. It requires commitment, perseverance and, very importantly, a strong purpose to keep on going. Us in a Bus has really motivated me both during the preparation and the run itself. I was proud to run on behalf of the charity, as the work done by Renée, Rich and the team makes an incredible impact on the lives of many people who need the support the most. I would love to stay in touch and keep on supporting them in the future.”

Thank you to all our runners, they have raised £1,700 so far, but the sponsorship money is still coming in and Santander have promised to match fund the sponsorship that their team raise for us, which is fantastic news!

If you fancy challenging yourself next year we will have more places available. The atmosphere at Brighton on the day is amazing and all the runners said what a great experience it was to run through one of our most iconic cities.

Apparently Brighton is one of the fastest marathon courses in the country so if you are interested in taking part in 2016 just email renee.canter@usinabus.org.uk for more details. Renée is pictured with this year’s team below – left to right are Rachel, Aleks, Renée, Svetlana, Sergeis and Rozie.
Heavenly Hosts in Covent Garden

Sunday 22 March saw the second co-hosted Concert we have co-ordinated with the Brandenburg Choral Festival. This year the concert was held at the beautiful St Pauls, in Covent Garden, which is known as the Actor’s Church and is surrounded by peaceful gardens. The quietness of the church was occasionally punctuated by the laughter from the piazza outside where street performers entertained visitors and tourists. Inside St Pauls choirs performed a series of Heavenly Choral Classics to a packed crowd.

The University of Reading Chamber Choir (pictured below left) and Felicitas Chamber Choir (pictured below right) from Essex came together at the end to bring the beautiful concert to a close. Our thanks go to the Brandenburg Choral Festival for the opportunity to raise our profile and provide us with a unique fundraising event.

Powered by ‘The Challenge’

Last year we signed up to be part of ‘The Challenge’, a project that brings young people together from all different backgrounds in a common purpose and, by offering new experiences, gives them the chance to learn new skills and meet new people. This helps them discover their talents and realise their potential.

We worked with a team of 16 year olds to help them to understand what life would be like for them if they had a profound learning disability or had challenges in communicating with others. They then designed and delivered a fundraising project to raise funds for The Bus Stop, our project developed for young adults. By working together they successfully raised £100 and proved that if given the chance young people can make huge contributions to their communities.

We’re pleased to confirm that we have signed up again this year as we believe that ‘Connecting Lives’ with the young people on our doorstep is important and that together we can build a stronger community.
‘Us’ in a Wordsearch

Got a spare 10 minutes?
Then try to spot these nine words that are associated with the work of Us in a Bus?
GOOD LUCK!

BERLINGO  BUSSTOP  COMMUNITY
EMBELLISH  FUN  LANGUAGE
MIRROR  OBSERVE  SOCIAL

Got a spare 10 minutes? Then try to spot these nine words that are associated with the work of Us in a Bus? GOOD LUCK!

You can find us  facebook.com/usinabusuk  @usinabus

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