IAN’S LASTING LEGACY

Receiving a legacy is bittersweet for Us in a Bus. We sadly miss our dear friend, but we are also so glad that their family recognizes the importance of the time we spent together with their loved one.

Victoria Goody (CEO), Tiw Raegening and Nancy Keeley (Interaction Practitioners) from Us in a Bus were delighted to accept the recent invitation to visit Hylton House in Sutton to celebrate the life of Ian Campbell with them. We had supported Ian there for nearly ten years, until he sadly passed away last year. Us in a Bus would like to thank Ian’s family for the generous cheque that we received from his estate. This will be used to support our work with people who have profound and multiple learning disabilities, to create opportunities for them to fully express themselves and live more fulfilled lives. Pictured below are Tiw and Nancy (center back) with the staff and residents of Hylton House, and inset Ian is enjoying a session with Us in a Bus Interaction Practitioner, Rosie Brookes and Sessional Worker, Gayle Howden.
Hello and welcome to our Christmas edition of Linking Lives. We’ve been chatting about Christmas a great deal in the office – mainly because quite a lot of us are like small children and are really quite excited about the whole thing. Christine is already promising to share with us all her natty range of winter themed jumpers and accessories, so you have been warned!

With the fun and celebration, there is also a downside that we’ve also been discussing. Whilst most of the people we support have profound and multiple learning disabilities (PMLD), many also have complex needs such as autism or sensory issues. Lots of people with PMLD appear to love Christmas – the foil decorations that rotate and sparkle can be captivating, and new and interesting activities take place in many homes. As many people reading this newsletter will know first-hand, many people with PMLD seem to enjoy the lights, colours and smells that come with the festive season.

However, many of the people we support with autism have a more nuanced and suspicious attitude to Christmas. We all know how hard this season can be for people who like things in their ‘correct’ place, those for whom it can be terribly upsetting to have a tree inside. Equally, the chairs may all be moved out of position to fit the tree in, resulting in people’s normal seats being out of place. The changes associated with Christmas can be enough to be a challenge for a profoundly autistic person. We’ll also be discussing Christmas regularly with the people we visit so that challenge of the change can be diminished. Predominantly, we’ll be using the principles of Intensive Interaction to support people at this time – and one principle is the importance of the pause – the silent gap that we must not rush to fill. The desire to want to share the excitement of Christmas is natural – but we need to leave moments of stillness.

The second challenge can be a sensory overload. The lights and noises coming from tree decorations can be unpredictable, surprising, and possibly even frightening; it is usually the only time that decorations are attached to the ceiling, and outside the home. For people who can struggle with the pattern on a jumper, imagine trying to process a spinning shining object on a tree, glinting in the light. Of course, almost every home is decorated with the very best of intentions, and lots of people love the novelty. The question for us is how to support a person at this time? Can we help acclimatise them to this? One top tip is to leave one room ‘free’ of Christmas, so that people with sensory overload can retreat to there, or have set times when the lights are put on. Also we’ll be using some Christmas and Winter themed songs to prepare people without the visual (over) stimulation. We’ll also be taking the time to observe how people react to the stimulation, and adjust if necessary.

A third challenge can be families. An increasing number of the people we support have regular contact with their families, but it can be difficult if they used to have visits, but as elderly parents pass on, they no longer do. It can be obvious that some people have many visitors and some very few. We’ll be trying to avoid conversations such as “I wonder if you’ll be seeing your brother at Christmas” unless we’ve checked with the care team first. We’ll try to be mindful of the potential emotional impact of periods of celebration (not just Christmas), as it is likely that we have heightened awareness of loss and bereavement at these times, as smells, sights and signs often trigger memories.

At this festive time, it is good to remember the diversity of the people we know so we can help them enjoy it in their own way. If, like me, you have young children then the excitement is already building and it looks like being a busy few weeks ahead. We’ll post pictures of any natty jumpers that we see!

I wish you and yours a very happy Christmas and best wishes for a happy and healthy 2017.

Victoria

*With grateful thanks to Jan and Lynne for their ideas!"
Super Parenting Improves Autism

Research on the Preschool Autism Communication Trial (PACT) was published in The Lancet in October. The trial was to investigate whether the PACT intervention had a long-term effect on autism symptoms and continued effects on parent and child social interaction. The research says that when parents are supported to interact with their children in an intensive way during play, there is a “sustained improvement in child autism symptoms and social communication with parents”. These new findings support the potential long-term effects and value of early parent-mediated interventions for autism.

Face to Face Exhibition

Our friend, Jo Shepherd, supports the residents in her art and music sessions at High Hurlands, a care home in Hampshire that we visit every week. Jo’s other talent is as a portrait painter and she has captured the essence of some of the people we know in oils and exhibited these at Charterhouse School in Surrey in October.

Jo said “My over-riding aim with this exhibition was to challenge any preconceptions that may exist towards people with profound disability and to convey the positive and inspiring facets of each individual personality.”

First International Intensive Interaction Week

The first ever International Intensive Interaction Week was held this year from 10 to 16 October. This was a week when people all over the world could collectively do something a ‘bit extra’ to promote the practice of Intensive Interaction.

Intensive Interaction is at the heart of the work of Us in a Bus and we were proud to support this week by doing a mail shot to over 750 people. Featured in the mail shot was information about 3 events happening during the Intensive Interaction Week – Janet Gurney, Director of Training held an Introduction to Intensive Interaction training course, a Choral Concert was held at St. Paul’s Church in Covent Garden to raise money for Us in a Bus and Jo Shepherd’s wonderful art exhibition (see item above).

VERENA MAKES GREAT IMPRESSION AT US IN A BUS

Us in a Bus were very lucky to have Verena Grys, a young lady from Cologne in Germany who is learning about Intensive Interaction, visit the team for two weeks in October.

She asked for the visit so she could shadow the team on their daily sessions so she could see Intensive Interaction in action.

The team loved having her with them and told Linking Lives “It was a pleasure to spend time and work with Verena. She is such an intuitive, warm and generous communicator. We were very impressed by her sense of observation and her ability to give feedback.”

Verena said she got so much out of the visit and told us afterwards “I’m feeling totally honoured that I could be part of your sessions! I had a great time with you and I’m impressed by the special way you work and communicate. Thank you for embracing me with so much kindness, happiness, patience and motivation. And thank you very much for letting me see what a difference music can make.”

Verena is pictured (on the left) at the Us in a Bus offices with (left to right) Joelle, Caroline, Janet and Victoria
Collecting information from the Interactive Sessions that we deliver has helped us build up a picture of the people we support, which will in turn help us to further develop our services and practices. But in this article you will see that it has also thrown up some really interesting statistics to help us paint a picture of the mileage the teams cover each week!

Currently we visit 216 people, living in 47 different homes across Surrey, Hampshire, Middlesex and London. 117 of these people are men and 99 women. Our biggest group, age-wise, are those aged between 51 and 70. In fact, 54% of the people we support are in this age bracket.

What our teams understand at each session is the unique challenges our people face, in addition to their profound learning disability. What these statistics show is the extent of these challenges across the population of the people we visit, as you can see below:

- 53% use a wheelchair
- 44% have epilepsy
- 31% have a visual impairment
- 12% have mental health issues
- 4% are diagnosed with Dementia
- 16% are diagnosed with Autism

The one statistic though that we know has swung in a hugely positive direction over the 25 years that we have been supporting people in our local communities is that **59% are now in contact with their families.** Although we haven’t formally measured this before, we know anecdotally that this has changed hugely over the years, and we also know what a positive impact this has had on the lives of the people we support.

Thank you to all our teams, and all those who helped provide this information, it really does help us think about how we do what we do every day and how we can improve.

Pictured right you can see the scale of the area we currently cover and where the homes we visit are located.
GETTING REAL BENEFITS FROM OBJECTS OF REFERENCE

As Us in a Bus Practitioners we often discuss how we can best support those we visit to understand that they are about to have a session? How can we maximise any positive anticipation they may have, or calm the anxiety of unexpected events? We believe that Objects of Reference may be helpful in this.

So, what is an Object of Reference? Well, it’s an object used to communicate a want, a need or a forthcoming event by direct association. At its most simple it could be a spoon that is given to someone to hold a few minutes before a meal time. In our case, an Object of Reference helps to ‘sign post’ that an Intensive Interaction session is about to start and denotes a separate activity, even if the location isn’t changing (e.g. if they are still in their wheelchair in the living room).

What object to use?

Well, there’s the question! These are the points that Us in a Bus considers when deciding what we might suggest:

• What are our client’s primary senses?
• How do they occupy themselves when alone?
• What kind of equipment do we mostly use when working with them?

If we think someone is more visually orientated or has a good understanding (especially of time), we may simply use our logo. We think carefully about how motivated they will be to engage with the object, as its purpose is to help generate a feeling of anticipation associated with our session. We believe Objects of Reference may be particularly effective with people who take a long time to process and find transitions difficult, and we think that for most people it is a positive process to try. Giving the people we work with as many ways of understanding what is going to happen is of course a good thing, even if, on the face of it, it may not be necessary.

In our experience it is the association with the object that is more important than the object itself. For instance, one of the gentlemen we visit is a deaf and blind man, who is often very focused on his sense of smell. He often doesn’t seem ready to engage when the session begins and takes a long time to emerge from his ‘inner world.’ We may suggest using a piece of fabric impregnated with a smell that he enjoys before we arrive. With regular use, we hope he will make the connection between this smell and our session, and have the opportunity to “look forward” to our time together.

When and how to use Objects of Reference for Us in a Bus sessions

Ideally, we would love each person who comes to our sessions, and who is using an Object of Reference for their Us in a Bus time, to be supported to explore their “object” prior to our arrival and to then bring it to the session. This helps cement their understanding of the connection between “us” and “it”.

Helpful and necessary stuff

Each person’s object may need to be cleaned regularly and be returned to its rightful place. Somewhere it can always be found and accessed easily is best, and, because consistency is so important, we find having personalised instruction sheets available, to share with everyone, makes it easier to communicate the information.

Equally, in order for it to be used effectively as an Object of Reference, it mustn’t be used for a secondary purpose, or its primary function might be lost or confused. The reason we suggest Objects of Reference is so that the people we support gain the maximum value from their session, so we’d love it if they could be supported to use them.

But even better, we would LOVE it if we could have a discussion about how you already use them, what ideas you have to make them really useful, and how we can work together to improve their use.
It struck me this week (with a bit of a shock) that I’ve been delivering workshops about Intensive Interaction for 17 years now. This probably adds up to between 800 and 900 workshops, which means well over 15,000 people have taken part in what have so often been eye-opening and exciting exchanges of perspective and experience.

You would think by now I wouldn’t get nervous before a workshop, but to be honest I would worry if I didn’t feel a shiver of anxiety before I launch into the introductions. And that’s because it is hugely important to me that I do justice to the subject matter!

Learning about Intensive Interaction and the way that I could respond meaningfully to people’s subtle communicative signals changed my working life (thanks Phoebe Caldwell, Dave Hewett and Melanie Nind!) giving me a deep sense of purpose and satisfaction – and I want as many people as possible to share that. Building bridges of connection and communication with people who really struggle with the fundamental steps of communicative development is important stuff, so I will probably carry on feeling a degree of anxiety about ‘getting it right’ for people.

Now…. when I feel anxious, my knees feel a bit wobbly. I might grip my marker pen a bit tighter or lean back against the sharp edge of the table behind me or clasp my hands. Do you recognise that sensation? It’s a pretty universal physical reaction to anxiety. What is happening is that when I’m anxious, my sense of proprioception (the sensory feedback that lets me know exactly where my body is and what it is doing) is momentarily inaccurate, and I cease to feel ‘anchored’; so I automatically and unconsciously increase the proprioceptive feedback I’m sending my brain – by clenching my fist, crossing my fingers etc.. It anchors me until my anxiety recedes. There was a brilliant TV programme recently on BBC 4 called Dissected – The Incredible Human Foot. It was about the anatomy of the foot and spoke about the sense of proprioception we all get through our feet – with fascinating evidence about how anxiety impacts the accuracy of that feedback. You can watch it on iPlayer (but I would fast forward through the first 50 minutes if you are squeamish as there is some very detailed dissection!).

Why am I talking about this? Well, understanding the sensory processing issues, which many of the people we support will experience on a daily basis, is often the bit of my Introduction to Intensive Interaction workshop that people get excited by.

A recent participant told me “This has opened my eyes about why people do the things they do – this really helps me to stop making assumptions and judgements”.

There…. we’ve moved straight from anxiety to excitement (and someone wise once said that there is only a deep breath between them). And of course, most of us will know someone with Autistic Spectrum Disorder who might show the same actions or vocalise in the same way whether they are anxious or excited.
Continued from page 6

So far this year I’ve had some great opportunities to share Intensive Interaction with many people, in some very different settings. Some workshops have been intimate - a young man and five of his personal assistants in his lounge, with him involved at every step as we explored together how we could respond to his breathing and rhythmic actions. Some have been a lot bigger, such as speaking in Rome at the Conference of Chromosome 18 Europe. The venue might have been vast, but the warmth of the audience and their willingness to grapple with headphones, relaying (almost) simultaneous translation in three languages was lovely. It lead to some great conversations after my presentation, including one about using Intensive Interaction with mashed potato or jelly as a way of celebrating a little girl’s repetitive hand-to-mouth gesture - and maybe sparking her interest in food as well as communication.

A development for me this year has been more ‘double-acts’ with Phoebe Caldwell (who amongst other titles, is Us in Bus’s Honorary President). It’s been an honour and a challenge for me to step into the occasional role as Phoebe’s co-presenter. We’ve found ourselves slipping into discussion on stage, sharing our different perspectives and approaches. A by-product has been becoming aware of each other’s style of non-verbal communication – when I see Phoebe’s walking stick twitching, I know my time is up! She has described us as the ‘Laurel and Hardy’ of responsive communication, and the jury is still out on who’s who! We spent a couple of days filming in Yorkshire earlier in the year, which will mean that Phoebe’s insight, knowledge and wide experience is available to as many people as possible. The film is currently being edited by the Caldwell Autism Foundation and will hopefully be available in 2017. We’ll keep you posted ......

Dates for your Diary ..... 

If you want to join me for an Introduction to the theory and practice of Intensive Interaction, or if you know someone who might (or should!) be interested, the dates for our open-to-all trainings in 2017 are:

Introduction to Intensive Interaction: 9 February, 2 May, 5 July, 8 September and 4 December
Next Steps in Intensive Interaction: 25 May and 1 November

To book contact Us in a Bus on 01737 764774 or email admin@usinabus.org.uk

A Soundscape “Untitled”

One of the projects that we embarked upon last year, to celebrate 25 years of Us in a Bus, was to create a Soundscape, using the sounds and voices of the people we support, recorded by us with their permission. This Soundscape is a unique window into the lives of a remarkable community of people who have profound and multiple learning disabilities. It is a snapshot of their lives, in their own ‘words’, and is a celebration of their incredible spirit and resilience. The nature of their conditions mean that many find communication to be a huge challenge, yet each person still asserts themselves through a diverse range of expressive sounds. It is a celebration of their lives through their unique sounds and voices, amplifying them individually and collectively.

The Soundscape is ‘Untitled’ because we simply want the people we hear to be able to speak for themselves, without any preconceptions. We hope it provides an alternative way for the people we work with to be truly heard. The Soundscape took 12 months to create and throughout the process the team of Us in a Bus Practitioners kept focused on one guiding principle – that it must be true to the individuals involved and their vocalizations must remain as they intended them, without any manipulation. The result is an incredible collage of their voices and sounds that holds the individuals at its center, following their emotional context at all times to create a sense of unity and continuity.

Us in a Bus have given a copy of the Soundscape to everyone whose voices were recorded and when visiting Joci, a lady we support, she was very withdrawn during her session so the team played the Soundscape to her. Anne Laney, Interaction Practitioner, told us “The change in her behaviour was immediate – the Soundscape really drew her out of her inner world”. ‘A Soundscape Untitled’ was created by Rich Myles, Marina Jurjevic, Russell Clark, Anne Laney and Tiw Raegening with the support of all their colleagues. We would like to thank all of the wonderful people whose unique voices were recorded for its creation. Listen to the Soundscape via our website – usinabus.org.uk.
WELCOME TO DOUG, OUR NEW TRUSTEE

We are delighted to welcome Doug Bennett as a Trustee of Us in a Bus. Doug isn’t a stranger to Us in a Bus, having already been involved in quite a few fundraising activities, but as a new Trustee he has already made a huge contribution, as Doug told Linking Lives.

“Having run a Half Marathon and trekked up Kilimanjaro to raise money for Us in a Bus, when I was asked to become a Trustee, I was honoured. And I thought great, no more wear and tear on the knees, instead I can just sit in Trustee meetings, listen and chip in occasionally. What a perfect way to be able to do something for this amazing charity that does so much good work locally. So I’m now a couple of Trustee meetings in, I have attended an Us in a Bus Away Day, got my face painted at the Sunday Funday, organised some much needed computers, will be setting up the pension scheme, and I anticipate Victoria will have some more projects lined up for me soon! Maybe fundraising at Machu Picchu next might have been easier!!”

Important visit by Surrey County Council

Us in a Bus were really pleased to welcome Sally Marks, the Chairman of Surrey County Council, to their offices at Redhill Aerodrome recently.

Sally used to chair the Council’s Committee on Adult Social Care so she not only understands the challenges the people we support face, but she is also aware of the challenges that we face in attracting funding to subsidise the services we deliver across the county.

Speaking after the visit, Victoria Goody, CEO, said “One of my priorities is to spread the word about the important work that Us in a Bus does. I was delighted to meet Sally to discuss our work and we also gave her the opportunity to observe one of our Interactive sessions in Earlswood.”

Trustee Award

We are delighted that our wonderful long-standing Trustee, Marianne Hecker, has been honoured with the Mayor’s Individual Trustee Award. Marianne, who recently retired as a Trustee of Us in a Bus, is also the founder of our Charity.

Julia Hancock, the Chair of our Trustees, accompanied Marianne along with interaction Practitioner, Joelle Francon-Parr. Julia said “It was a lovely evening and a well deserved award for Marianne. It was great to see and meet so many volunteers from all sorts of charities.”
MEET THE PEOPLE BEHIND US IN A BUS

In this edition of Linking Lives we talk to Russell Clark, who has worked for Us in a Bus as an Interaction Practitioner for four and a half years.

Here’s what he told us …..

Q Where did you work before joining Us in a Bus?
A I worked in a residential setting as a support worker with adults who have autism. I used Intensive Interaction whenever I had the time and it helped me form very close relationships with the residents.

Q What does an Interaction Practitioner do?
A I always aim to give the people we visit a clear message that any emotion they may be feeling is valued and met with a response that gives them what they need; be it comfort, reassurance, excitement, humour - to name just a few. I also have a particular interest in sensory processing issues and every person has their own unique experience of this.

Q What is the most amazing aspect of your job?
A To feel that I’m discovering treasure; when one of the people we support does or says something completely new or unusual and it was completely spontaneous and self motivated, but we helped to inspire it.

Q What do you do outside of work?
A I sing in a choir. We sing various gospel songs, African harmonies and folk songs. I recently became a Dad, so leisure looks very different now! Theo, who is four months old, loves being taken on walks in the country. To see his eyes looking up at the trees as I carry him in front of me fills me with joy.

Q What’s been your greatest achievement in life so far?
A That’s easy - becoming a father!

Q Who do you most admire in the world and why?
A Jeremy Corbyn for being so stubbornly principled, but also pragmatic in such a hostile environment.

Q What is your most favourite food?
A A packet of Bombay Mix with an ice cold craft beer on a hot summers day after a hard days work – followed by a good curry of course!
Sylvanian Families get muddy for charity!

The residents of Sylvan Way ‘The Sylvanian Families’ took part in the ‘Back to the Trenches’ 12k mud run at Priory Events in Nutfield to raise money for Us in a Bus.

Despite the pouring rain, muddy and smelly conditions they completed the full 12 kilometers and raised over £570 for us.

Thank you all so much from everyone at Us in a Bus!

Half Marathon success for Victoria and Lizzie

Victoria and her friend Lizzie ran their first ever Half Marathon in Maidenhead in September and, as you can see in the picture of them with their medals, they were absolutely delighted when they made it to the finish line!

Victoria said “We were running for two very deserving charities, Us in a Bus and The Brigitte Trust. And I’m really pleased to say that we raised nearly £2,000! We would like to thank everyone who sponsored us and those who supported us on the day, it really did make a difference.”

The Brigitte Trust is an independent registered charity which was set up by Dorking resident, Brigitte Watkin, to support people at the end of life in their own homes, offering support and respite to their carers and emotional support to the wider family too.

TWO MORE RUNNERS NEEDED FOR THE 2017 BRIGHTON MARATHON

The Brighton Marathon is an important fundraising event for Us in a Bus and once again we have purchased five charity places for the 2017 Marathon for runners to raise funds for us.

Renowned for its buzzing atmosphere and roaring crowd support The Brighton Marathon is one of the UK’s favourite 26.2-milers. With a stunning backdrop of the sea in one of the country’s most vibrant cities, the race gets bigger and better every year.

Three places have already been taken, but we are still looking for two more runners. The Marathon will take place on Sunday 9 April 2017, so if you are fit and able and want to run to raise money to support the incredible work that Us in a Bus does, please contact Renée Canter on 01737 764774 or email renee.canter@usinabus.org.uk.
Us in a Bus held it’s first Family Funday at the end of August and, despite the wet and windy weather, it turned out to be a huge success, raising over £700!

The event was held in the grounds of its offices at Redhill Aerodrome and was opened by Sophie King, the current Miss Surrey.

Family entertainment was provided by the superb five piece band, Redlands, who played all our favourite songs. There were also plenty of stalls, a raffle with some amazing prizes and a bouncy castle which kept the children amused.

“I am delighted that, after months of preparation, our first Family Funday was so successful.” said Victoria. “It was a great team effort and I would like to thank the organizing team, the staff and Trustees who helped on the day, our BBQ Chefs and all the local organisations who donated such great prizes for our raffle.”

Fundraising helps us to continue to deliver our services and the £700 raised will keep one of our vans on the road for 4 months.
INSPIRING WORDS

The inspiring words we would like to share in this edition of Linking Lives were written by the author, John Joseph Powell, and we think they reflect the work that Us in a Bus does every day.

“It is an absolute human certainty that no one can know his own beauty or perceive a sense of his own worth until it has been reflected back to him in the mirror of another loving, caring human being.”

Why I ♥️ my job!

We have asked all our staff to tell us why they love their jobs and we will be sharing their thoughts with you in future editions of Linking Lives.

In this edition, read what Marina Jurjevic, Interaction Practitioner, has to say ......

“I adore my job because it focuses on people and their right to communicate in their preferred way.

We listen and respond to what our partner communicates to us.

We know that communication and the right to be heard is a basic human need.

We thrive to link with the people we support and explore their world with them.

In such endeavours we extend our communication into the realm of arts. This is, I strongly believe, the best way to connect, to examine our intrinsic values – it is what makes us what we are.

I learn so much from the people we support, and that definitely enriches my life.

I feel proud and thankful that I am involved in something so humane and important; something that is inspired with and has in its foundation the Declaration of Human Rights.”

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You can find us facebook.com/usinabusuk @UsInABus

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