

## Active Listening in Action!

### What's in this Newsletter?

It is sadly still common to hear comments like "He/ she doesn't communicate", when what is really meant is that he/she doesn't communicate verbally. We all have a basic human need to communicate and connect with each other, and do so in a range of ways. Children and adults who don't speak have the same communication needs as the rest of us – but need extra support and different ways to help them tell us what they want and how they feel. This newsletter focusses on how we can all get better at creative and positive ways to help children and adults communicate, and share their views and experiences. The lead article 'Stop, Look and Listen to Me' describes CBF's work engaging with young people and we give an example of how one young man's views were listened to in that project (page 2). We feature an article on a service provider's approach to getting to know people they support (page 3) and one family's experience of residential college (page 5).



Viv Cooper, CEO of the CBF

Too often there is an assumption that some individuals can't contribute. Instead, our starting point should be that everyone communicates, and everyone has a right to be heard. The challenge for us is to find ways to make that happen for everyone. And really listen.

### Stop, Look and Listen to Me

In 2014, we ran a video competition (as part of the Early Intervention project) to ask children and young people with learning disabilities what they enjoy and what helps them to do the things they enjoy. The winner, Alfie, told us about what he enjoys, then about who helps him enjoy those things. When his Mum asked him, "...who else helps you Alfie?" He says "Me". Click here to watch the [video](#).

How often do professionals and service commissioners stop and think about what it is like to be 'Me'? How far do they 'walk in the shoes' of children and young people of severe learning disabilities?

Some organisations provide great examples of engagement with disabled children and young people, but how often is this inclusive of children with severe learning disabilities?

We took forward the 'Stop, Look and Listen to Me' project because we felt there was a real gap in meaningful consultation with children and young people with severe learning disabilities and behaviours described as challenging. Behaviour itself is a form of communication, but far too often that communication is only noticed when it becomes too challenging for people to deal with and even then, the underlying need is not always identified or addressed.

The 'Stop, Look and Listen to Me' report (due to be published soon on the Paving the Way [website](#)) by the Challenging Behaviour Foundation sets out the methods we

'Stop, Look and Listen to Me' Methods of Engagement was developed in conjunction with the Tizard Centre and used under their supervision. It involves:

- ◆ Interview with the young person using Talking Mats;
- ◆ Direct engagement in an activity with the young person;
- ◆ Structured observation;
- ◆ Interview with family carer.

used to engage with children and young people, what we found out from that engagement and what we have learnt from the experience.

The report sits alongside a resource we developed with Mencap called 'Valuing the Views of Children with a Learning Disability' with examples of engagement which services might wish to replicate. It can be found [here](#).

The Transforming Care Programme rightly emphasises the need to engage with children and young people with learning disabilities. However, we know that engagement with disabled children often takes the form of focus groups, which are not appropriate for children who do not communicate verbally. Excluding one of the key groups at risk of admission to Assessment and Treatment Units can't be acceptable. We would urge all Transforming Care Partnerships to learn from the evidence and best practice in these two reports, so local support for children with learning disabilities in the future is guided by the experience and wishes of children with severe learning disabilities and their families.

## Engaging with Samuel



Samuel lives with his parents and sister. He has severe learning disabilities and autism, and he participated in the CBF's Stop, Look and Listen to Me direct engagement project.

The researcher visited Samuel at his home, and spent time being in his environment to ensure he felt comfortable in their presence and interacting with them. One method the researcher used was to gather Samuel's views and experiences to look for 'observable indicators' that were unique to Samuel. Samuel's family carers were asked about the observable signs (such as facial expressions, eye contact, interactions, speech or noises, body language, specific behaviours) that Samuel displays when he is in different moods. These indicators were used to structure the observations to find out his views on what he likes and

dislikes, and what is important to him.

Samuel's parents described some indicators of his happiness, enjoyment and engagement as: having a huge smile, laughing, making lots of eye contact with others, skipping around, jumping up and down, flapping his arms and hands, saying "happy know it" and singing songs. Whereas, some indicators of un-happiness and non-engagement identified were: crying, screaming in a high pitch, leaving the room, throwing items, stamping his feet, hitting his head with objects, saying "no thank you please" and "bye-bye".

The researcher used these observable indicators during structured observations, and this showed that some of the things Samuel appeared to enjoy were: being on his swing, being visited at home, interacting with others (in particular when others repeated what he said, and laughed with him), having people's undivided attention, being sung nursery rhymes, eating, hugs with his parents and Intensive Interaction.

He did not appear to enjoy: not being able to express that he wanted something or not being understood by others, waiting, not having a person's full attention and being asked to complete work at home.

Observing what Samuel's behaviour communicates is the key to finding out what he thinks about specific aspects of his life. And most importantly, gathering Samuel's views and preferences in this way is essential in getting his support right and planning his future support.

## Newsflash

**CBF Positive Behaviour Workshops** are available free to family carers of adults with a severe learning disability whose behaviour is described as challenging, who have personal assistants through Direct Payments. Family carers and personal assistants are invited to attend in the following locations in **January** and **February** 2018:

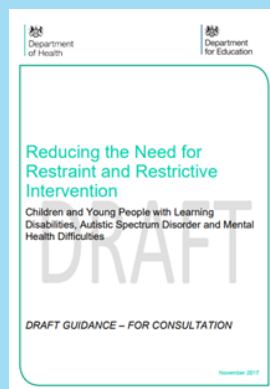
**HALIFAX** – 15th January (family carers) & 22nd January (personal assistants) and 19th February (all)

**MANCHESTER** – 10th January (family carers) & 11th January (personal assistants) and 26th February (all)

**SUSSEX** – 16th January (family carers) & 22nd January (personal assistants) and 22nd February (all)

Funded by Skills for Care, the workshops are run in partnership with local organisations. To register, contact [info@thecbf.org.uk](mailto:info@thecbf.org.uk) or **01634 838739**.

## Use of restraint consultation



The Department of Health is seeking views regarding draft guidance on reducing the need for restraint and restrictive intervention for children and young people with learning disabilities, autistic spectrum disorder and mental health needs.

Your views are important. To view the draft guidance, please go to:

[www.gov.uk/government/consultations/restraint-and-restrictive-intervention-draft-guidance](http://www.gov.uk/government/consultations/restraint-and-restrictive-intervention-draft-guidance)

From this page, there is a link to the online survey, through which you can give your views.

**Who are the CBF?** We are the charity supporting those with severe learning disabilities whose behaviour is described as challenging.

## Download our free resources

We have a wide range of resources for family carers and professionals available on [our website](http://www.thecbf.org.uk)

## Finding Ways to Communicate with Young People: A Provider Perspective

**Linda Fish** is Operations Director and Head of Services at Alderwood LLA : a provider of bespoke, integrated packages of care, education and development in a small 'family' type setting. Linda's article shows the fundamental impact of good communication. For Tom, this meant the avoidance of admission to a secure hospital and the development of a good quality of life in a setting where people understand, and are able to meet, his unique wishes and needs.

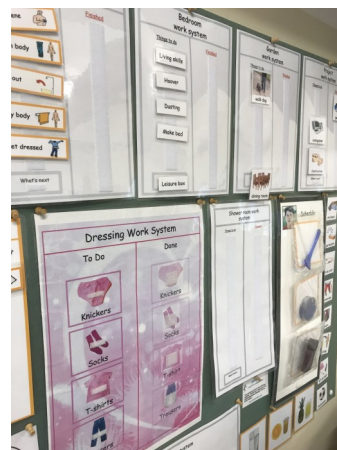
Before ever meeting someone with autism and / or learning difficulties, we arm ourselves with as much information about that person as possible. There is generally some tiny detail among all the documents, graphs, reports and opinions that are sent to us, which we can focus and build upon.

For example, a good few years ago now, we were introduced to Tom; whose mother had died when he was four years old. His baby sister had to be taken into care because his father was unable to look after a very young baby and his son whose behaviour was challenging.

Tom and his father were living in a very small flat in a deprived area where the neighbours were not at all sympathetic to Tom's needs. There had been complaint after complaint about the noise coming from his father's flat. Although non-verbal, Tom made noises that his neighbours likened to that of an animal. The neighbours were unforgiving and demanded something 'be done'. They considered that it wasn't right to have somebody 'like that' living in their neighbourhood, that he was a 'freak, scary and evil'. The crux came when Tom managed to escape his father's care while out in the communal garden, he found his way into a neighbour's house through the open back door. Knowing (because of a previous altercation) that Tom was terrified of dogs, the neighbour allowed his large, unfriendly and heavily built dog to chase the young man out of the house and down the road. He was picked up hours later by the police and put into the care of social services.

Although we read everything that is made available to us, we are very insistent that we manage assessments by working 'hands on' with the young person. On this occasion, we were asked to assess Tom in a very small and confined space. We discovered very quickly that Tom had an intense fascination with women's hair. When we met him, he knocked us to the

ground so he could touch and pull it. Fortunately, we remembered reading prior to our visit, that Tom used to like to dance when his mother sang nursery songs to him as a toddler. As soon as we started singing, he stopped the hair pulling, and started to clap and dance.



We quickly got back on to our feet and continued to sing for the next five days, during which time we managed to put a halt to him being transferred into a secure hospital and sought agreement that he be allowed to come in to our care instead. It wasn't ideal timing, as we were about to move our children's residential school into a new building, but we managed - and more importantly, Tom managed.

Tom came into our care as an 11-year-old boy. He remains in our care as a man of 21. We no longer have to sing to him 24 hours a day, as he has learnt to use an individualised visual communication system. Visual communication used consistently is as necessary to this young man as a wheelchair is to somebody whose legs do not work. He is totally reliant upon it to get him through the day. He has learned so much and come so far over the years, but remains completely unique. He isn't somebody who can be 'slotted' in somewhere and hope that he will fit because he just won't.

I always think back to the day we first met him and how easy it would have been to make the decision to say "No. Sorry. We can't help." But we didn't. We found a way to communicate, and the rest is history.



**Linda Fish**  
Operations Director & Head of Service

Please note, the name of the young person in this article has been changed to ensure anonymity



## Your questions from the Email Network

**Q:** My son is in receipt of Employment and Support Allowance (ESA) and is in the Support Group. He lives in residential care, has autism, a learning disability and behaviour that challenges. Three years after being granted the benefit, I have been sent yet another *Work Capability Assessment* form! It is very time-consuming having to fill this in and send evidence reports. His condition is lifelong. Has anyone else had to deal with this issue?

**A1:** My daughter is in the Income-related group for ESA: she has a 'Permanent Disability' form signed by the GP, gets free dental treatment and prescriptions, and I have 100% exemption from deputyship fees. We have also never been asked to fill in any more ESA forms since she was awarded it about 5 years ago.

**A2:** I too had this problem, I hadn't realised that there were two groups when the ESA first transferred from the Incapacity Benefit. I'm afraid, completing these lengthy forms have become part and parcel of our lives. I agree dealing with all appointments, forms and everything else associated with our sons and daughters is a full time job in itself.

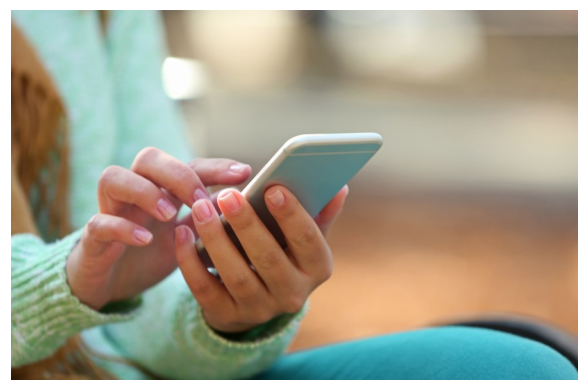
**A3:** We started on this adventure in 2009, hauled up before an assessor despite sending copious amounts of paperwork. Fortunately, our son acted in glorious oblivion to his surroundings, reciting nursery rhymes to himself. Our son has been assessed twice since, although never subjected to an interview again. We were surprised that the latest covering letter for the *Capability for Work Questionnaire* (ESA50) stated 'send any recent reports if you have them, but don't commission any'. I would recommend everyone just plans that any day they could be re-assessed, and think about the evidence they might have that is relevant and accurate now. Be prepared! Our son would have nothing to live with without these benefits. They review the ESA payments every year as our son was left some money by relatives.

**A4:** There are two types of ESA: Contribution-based ESA and Income-related ESA. Both types have a Work-related Activity Group and a Support Group. [www.gov.uk/employment-support-allowance/types-of-esa](http://www.gov.uk/employment-support-allowance/types-of-esa) As far as I am aware, there is no difference in payments if you're in receipt of either contribution-based or income-related ESA. However, the Support Group pays a higher rate of ESA compared to the Work-related Activity Group. There are pros and cons to both type of ESA. However, if you have no meaningful assets, receive no income other than benefit income and are in the support group, then almost certainly you're better off being in the income-related category.

**Want to ask your own questions or share your experience?**

**Join the Family Carers' Email Network:** [click here](#)

**The CBF also runs a Professionals' Email Network, to find out more and apply to join,** [click here](#)



## Our Experience of Residential College



*Pam Pacey writes about her daughter's life at residential college and the difference now that she has the right care and support.*

Rachael is our middle child, between two brothers. She has a rare genetic condition that presents as a severe learning disability, autism, an eating disorder and mild self-harm. As a child, Rachael lived at home, attended the local special school and went on family holidays abroad without incident. When her brothers both went to university, **we felt a residential special college placement would help Rachael gain independence.** We visited colleges, and chose the one we felt was most suitable and closest to home. However, during and after her college years, behaviours that challenged and self-harm intensified.

We immediately had concerns about the residential special college as they insisted that we had no physical contact with Rachael for the first half term. They didn't provide any regular communication with us and, as she cannot use a phone, we were completely cut off. The college wanted to take Rachael as a blank canvas. However, she can't talk and uses very few idiosyncratic signs, so communication is very difficult. Despite this, they were not interested in finding out any useful information about her.

The lack of communication from the college became a major issue. They held annual reviews without telling us about escalating behaviours, or their inability to deal with them. They didn't look for triggers or take into account events she might find upsetting. **Rather than seeing Rachel's behaviour as a desperate attempt to communicate at a very basic level, they saw it as something to be punished and eradicated.** Overall, it seemed the residential college didn't understand our daughter's needs and were unable to provide the support that she required. Instead of moving on and becoming more independent she became fearful and less tolerant, and there were quickly escalating incidents of challenging behaviour at the slightest setback.

Our greatest regret is that we handed Rachael over to people we thought were professionals and they let us down. We feel that we also let her down because we allowed them to blame her, try to change her and punish her. When we finally

withdrew Rachael, there was no exit strategy or suggestions for future plans. When my husband went to collect her things, the principal refused to see him and told his secretary to say he had washed his hands of her!

The Lenehan review of Residential Special Schools and Colleges is considering their future role. I think that residential special colleges could be useful to support the transition of young people to supported living in their community and to understand how someone would be best supported as an adult. To achieve this, the residential college would need to **work closely with parents and others to understand the young person, and to develop clear and detailed personal plans**, including communication and health needs. Positive Behaviour Support (PBS) should be at the heart of all decisions and drive all strategies. A key worker working closely with everyone would ensure that these individual plans are jointly agreed and followed. Communicating regularly with parents, they would make sure that any problems are raised quickly and solutions found before they escalate.

Colleges should work with young people, rather than dictating to them. They should discover what activities the student enjoys and have a planned progression based on their needs. -Instead, we found that Rachel's care was too often based around the needs of the college. In her first year, she lived in a group of four rooms with three staff members, but she was moved in her second year to live in a group of twelve rooms with two staff members. This was not because she had progressed, but because the new intake were all boys and this was the only way they could all fit in.

For the last six years, Rachel has been supported to live in her own flat with 24-hour 1:1 care. Through the Challenging Behaviour Foundation **we discovered PBS and this approach has greatly altered her life for the better.** She has a very detailed communication passport and staff are trained to use it and PBS principles. Social stories using personal photos help Rachael cope with difficult but inevitable events, such as when her favourite carer went on maternity leave.

Rachael will always be Rachael. She will continue to have challenges in her life, but we and her staff now have the tools to communicate with her more effectively so that she can lead a very full and active life of her choosing in the local community.

**Pam Pacey, Rachael's mother**

# Supporters' News

## Fundraising for the CBF needn't be a chore!

The CBF has helped me and my family ever since my son was sectioned at Winterbourne View. I've always wanted to give something back and I realised that my experience of being involved in another charity would help me to do so with ease.

Times are tough and seeing the CBF being affected by this has been very hard for a family that has been so deeply touched by their work. I struggle to find opportunities where I can afford to help and I know that I'll never be able to pay the CBF back for all that they have done for us all. I found a way to help at no additional cost to me and have since raised £300 with a few extra clicks on an internet site.

**Easyfundraising** is an additional search bar covering many online shops across the internet. It can be used for online shopping for insurance, holidays, food, gifts and belongings. It is as simple to use as typing in the shop into Easyfundraising's search bar and doing your shopping as normal when redirected to the site. A percentage donation is then sent directly to the charity of your choice. Donations from the site can be as little as 1 or 2%. Your own shop costs you no more, but the money raised adds up over time and is a significant and effective donation for the CBF.

In 2008, I co-founded a Mental Health charity funded solely through public donations. We needed to be resourceful and creative with our fundraising ideas and so we were. In difficult times, the charity ran for four years and provided opportunities people with mental health needs to access workshops and outings. Our money raising ideas included the usual coffee mornings, sponsored events and car boot sales, as well as asking those running regular coffee mornings if they would give their collection to our charity as a one-off. One of our biggest fund-raisers was through simply asking people to take a cake to work and sell slices (much less organisation than the usual bake sale).

Fundraising doesn't have to be all about running marathons, there are plenty of ways to get involved. For some of them, you don't even need to leave your seat! The CBF needs our help, and I know there are plenty of people out there who want to do all that they can. Sometimes, just the little things can make a big difference and sometimes thinking outside of the box is the best way to go.

Claire Garrod-Pullar, CBF fundraiser



### Helen's London Marathon!



CBF Finance and Fundraising Lead Helen will be running in the London Marathon on 22nd April

2018.

She'll be raising vital funds for the CBF. Every donation counts, however big or small.

Please visit Helen's [fundraising page](#)

*Good luck Helen!*

### Volunteering



We're delighted to welcome Isabelle as CBF's new volunteer editor of Challenge! We think she's done a great job with this edition and hope you do too.

Thank you to all our volunteers, who keep the CBF running smoothly!

### Hundred Club Winners



Recent winners of the £25 prize were:

**August 2017** - M Magadan, London

**September 2017** - M Matthews, London

**October 2017** - T Murphy, Kent

**November 2017** - H Hawkins, Kent

Want to join for just £12 for a chance to win each month? Email [info@thecbf.org.uk](mailto:info@thecbf.org.uk)

### Can you help us?

We rely on donations, grants and fundraising to continue our work helping families. Find out how you can help us on [our website](#)

#### Disclaimer

While every care is taken in the compilation of this newsletter, the Challenging Behaviour Foundation cannot be held responsible for any errors or omissions, nor accept responsibility for any goods or services mentioned.

The Challenging Behaviour Foundation. Registered Charity No. 1060714 (England and Wales)

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**The Challenging Behaviour Foundation**  
making a difference to the lives of people with severe learning disabilities

### **Please help us to 'Make a Difference'**

"Individuals with severe learning disabilities and behaviour described as challenging are likely to achieve less at school, be excluded from local education and leisure activities, receive no training or support to get a job or build a life for themselves. **In short, they are amongst the most vulnerable and disadvantaged in society**"

*Prof P McGill, Tizard Centre*

"When you have a child with a learning disability, you just expect the system will swing into action and help my family to help my son – but sadly I soon realised that wasn't going to happen". 'Families are often left on their own to struggle without the support they need. The Challenging Behaviour Foundation (CBF) exists to change this'.

*Viv Cooper, Founder & CEO*

*"How do I explain or ever put a price on what it meant to have someone to hold your hand and truly understand you when you are going through the darkest of experiences? What I discovered was they (the CBF) enabled me to grow in confidence with the information they provided us. Our strength was reinforced by knowing a charity with great integrity believed our family struggles and were not daunted by the magnitude of the problem but helped us find solutions. They sourced endless credible resources to assist me to effectively challenge abusive practices. Important strategies such as Positive Behaviour Support Courses and Person Centred Plans were introduced to me via CBF which has in turn helped to make a huge difference to the quality of my son's life and a huge reduction of behaviour that challenges."*

**Family Carer**

Please make a [donation](#) to the CBF to so we can support more children, young people and adults with severe learning disabilities with behaviour described as challenging, and their families.



*"There are so many awful things happening to people with a learning disability and their families. I can't thank you enough so far for your patience and your support through an incredibly difficult period. Without the CBF to turn to for invaluable advice and family support I can imagine how parents struggle to cope."*

**Family Carer**

Your donations will help us continue to provide practical information and support to **families free of charge**. Families need the right information at the right time and money should not be a barrier to them receiving this.

- £5 will allow us to print and post an Information Pack
- £10 will allow us to provide one of our practical information DVDs
- £25 will fund a Family Support Worker to support a family for an hour

You can [donate](#) a single amount or set up regular giving [online](#) using the donate button above. You can also send a cheque to: Freepost RRRH-GCJS-BRZJ, Challenging Behaviour Foundation, The Old Courthouse, New Road Avenue, Chatham, Kent ME4 6BE

**Thank you – from everyone at CBF and the families we support**

**Your donation really will make a difference.**