

Challenge

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The Challenging
Behaviour Foundation

Communicating and connecting....

To read online, please see:
<http://bit.ly/CBFNewsletters>

The pandemic has had an impact on all our lives and has made us think more carefully about the things that are most important to us or that we previously took for granted, like seeing friends and family, social events and shared celebrations. And all of these involve forms of communication, so we have had to adapt to things being different and to find new ways of connecting with people.

But the impact and the opportunities to communicate and keep connected have not been evenly spread amongst us. Many of us have been able to adapt, using get-togethers on Zoom or Teams. Although they are not the same as seeing people in person, they have enabled us to keep connected. But not everyone has internet access or the means to connect digitally - and the gap between those who do and those who don't has grown wider, with many people having less access to information, less social contact, and more isolation.

Equally, for some children and adults who live with communication challenges the pandemic restrictions have had a major additional impact on already existing communication and connection inequalities.

The covid restrictions have given society an insight (albeit a very limited one) into the world that many individuals with severe learning disabilities inhabit - where communicating with others, sharing thoughts, feelings, ideas, memories, fear and joy has been difficult - and we have experienced the isolation and anxiety that this creates. We now have an opportunity to ensure that we do all we can (and we can do a great deal!) to find ways for children, young people and adults to communicate their feelings, their likes and dislikes and what is important to them, so we can empower them and better support them in ways that improve their quality of life.

This newsletter shares information and examples of good practice from families and professionals and has been posted in hard copy to ensure that we provide accessible information in different formats. Do get in touch if you read about something you would like to know more about.

Vivien Cooper
Family carer and
CEO of the CBF



Resources in this issue

All the resources featured in this edition of our newsletter (and many others) are available on our new website.

We are delighted that funding from the National Lottery Community Fund has enabled us to develop our new website as part of our 3-year [Getting it Right](#) project. The new site has improved access on phones and tablets, as well as laptops, and is more user-friendly with resources that are easier to find.

Visit the new website at the same web address: www.challengingbehaviour.org.uk for news, opinion, information, resources, opportunities, and support!

Contents

The power of communication	2-3
Seldom Heard project	4-5
Building positive relationships	6
We are recruiting Local Champions	7
Working in partnership	8-9
The CBF now offers peer support calls	9
Having choices and preferences	10
Your question from the email network	11
Practical communications resources	12-13
AID- ITT London service	14
Family carers not online? What we offer	15
Thanks and making donations	16

What is the CBF? We are a charity supporting children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.

The power of communication

Robert Steeples (a Care Manager) and Amy Steeples (a Speech and Language Therapist) tell us about communicating with their sister, Claire (who now lives in her own home and has a severe learning disability).

What would a world be like without communication? Think about this morning; how many times did you communicate before 9am?

We communicate all the time for various reasons because human beings are programmed to seek out others and make our needs known, to share ideas, and to share problems and to hopefully find solutions. It is a fundamental and basic need in our lives.

So, what can happen if you are struggling with your communication?

Augmentative and Alternative Communication (AAC) strategies are additional ways of supporting someone to communicate. One particular AAC strategy has completely changed the quality of life for our sister. The tool is known as Picture Exchange Communication System (PECS); it is a communication tool which uses pictures and symbols to help an individual initiate communication and conversation. It must be implemented in a controlled, personal-centred and planned way to ensure its success.

PECS originated from America and was started for pre-school children who had a diagnosis of autism, helping them to begin communicating what they wanted and needed. It is now used worldwide and each person using this system has a personalised folder of images that are useful and relevant to them. To communicate, they select an image and hand this to the communication partner to request that item, for example they may find and exchange an image of a glass of juice to request a drink. As the individual becomes confident using the system, this can be built up to create sentences, to request more complicated items or even to comment and communicate thoughts and ideas about a subject such as on a walk – 'I see a bird'.

Our sister Claire has a severe learning disability. As Claire got older and moved into adult residential

settings, the care and support she had previously received changed. One-to-one support was almost non-existent and previously nurtured skills were lost and forgotten. Claire became isolated, as support and encouragement stopped. Her anxieties increased hugely and so did her challenging behaviour. She had no control or choice over her day, had no way to communicate and no supports were put in place to help her understand what was happening. Staff regularly reported she was too old to learn new skills and was seemingly written off. This escalated over the years that she spent in adult social care and led to her pulling out half her hair. She went on to develop strong challenging behaviours that we still see at times today.

When she was 30 the family made the decision that enough was enough and they bought Claire a small house and began setting up a caring environment around her that was person centred to meet all her needs, one of the biggest being her communication.

Claire was introduced to PECS by Robert and he created a folder of symbols to include all her favourite things and most treasured items.

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Claire's PECS book

The power of communication - continued

Slowly he built up her knowledge of the images and repeatedly they practised exchanging for items until Claire realised the meaning and benefits of the exchanges. This changed her life. All of a sudden, she had the beginnings of control and had a voice that was being listened to. Her challenging behaviour slowly reduced, her confidence grew and finally, so did her hair. In her 30s, Claire was able to learn a new way to communicate and create a new life because she had the right help and support around herself. Her motivation and desire to communicate was always there, it just needed to be unlocked.

Since then, Claire and her family have spent time campaigning for personalised care and the rights of adults with learning disabilities, particularly for support around communication. In 2015 they were invited to London to meet with Sir Simon Stevens, head of the NHS to talk about personalisation in the adult care world. Claire communicated with him using her PECS and showed off her newly found voice.

Now, at age 43, Claire's PECS book is central to her life. Throughout the day she will select images of activities she would like to do, items she has lost, to request a snack or drink or even to ask for bath and bedtime. She knows that when she uses her symbols, she can communicate what she needs and that this will be listened to and get a response. At times she can't always have what she has requested such as numerous ice creams! But that begins a conversation and she can be helped to understand why that can't happen or build it into a schedule for later in the day. This has become even more prominent recently with the arrival of Covid-19. Routines stopped overnight and many of the

activities Claire loves have been closed. It has been a challenge, but Claire has been so resilient and has adapted to these changes, finding new interests in crafting, baking, dog walking and a huge love of virtual sessions!

Claire's life has changed vastly and all for the better. She now has a life, not just an existence, and most importantly, she has the power of communication.

Robert and Amy Steeples

This article has been adapted from an article first published for Carousel, the Diplomatic Service Families Association magazine. Read the complete article on our website:

www.challengingbehaviour.org.uk/information-and-guidance/person-centred-support/the-power-of-communication

Read more about Claire's story on the Your Stories part of our website:

www.challengingbehaviour.org.uk/news/my-life-my-way



Claire meets Sir Simon Stevens

More about communication

Find out more about how improving communication can reduce challenging behaviour by reading our webpage and information sheet: www.challengingbehaviour.org.uk/information-and-guidance/person-centred-support/communication

Or request a printed copy by phoning 01634 838739.



Seldom Heard project

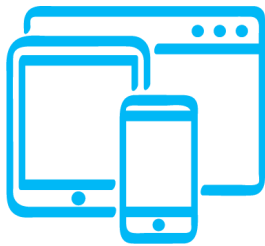
Everyone has the right to have a say about their own life and about wider issues that impact on them. This includes children, young people and adults with severe learning disabilities and profound and multiple learning disabilities. We know that these peoples' perspectives are seldom heard.

In 2021 we published a report called 'Stop Look and Listen to me'. This report details methods developed by the CBF and the Tizard Centre to understand the views and perspectives of young people with severe learning disabilities. We did this as a pilot for the Seldom Heard project, which builds on existing good practice around listening to and involving people with severe and profound learning disabilities.

Throughout the Seldom Heard project we have been supported by an advisory group which includes family carers, providers, Mencap and PMLD Link. This article reflects on our learning to date.

The pandemic

This NHSE-funded project started in early 2020. However, as the COVID-19 pandemic progressed, it became apparent that the project needed to take place online, particularly as people with severe or profound learning disabilities had been identified as clinically extremely vulnerable. We realised that the need for this project had become even greater as a consequence of the pandemic.



To complete the project virtually we decided to replace in person visits with virtual meetings with communication partners and the individual they support where possible. Communication partners are family carers or paid supporters who are very familiar with the person they support.

Whilst we were confident about our ability to work through communication partners, we also needed to be cautious of, and sensitive to, the challenging circumstances facing everyone involved.



Identifying communication partnerships and explaining the project

We had help from our advisory group to clarify the individuals we were looking for in the project. We then advertised the opportunity through our existing networks. We then had an initial phone call with interested people. We were aware that paid supporters and family carers have limited time available and so the initial phone meeting was brief.

Those still interested were then contacted to go through consent processes which involved best interest processes and independent checks. For the best interest process, we needed quite a sophisticated understanding of each person's communication and interaction skills, particularly around indicators of enjoyment and distress.

Participants varied in terms of communication partner (e.g. family member or paid supporter), age (children and adults), where they lived (e.g. at home with families, in residential adult services or residential schools) and whether they attended any day provision. Some communication partners had daily contact with the individual and some had less frequent contact.

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Seldom Heard project - continued

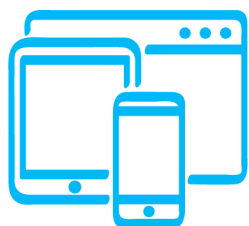
Moving forward

Our online engagements have now started, and we aim to report our findings this summer. We are co-producing this process with communication partners, identifying what the focus of gaining views should be and any opportunities to find out views directly from the individual. This might include asking communication partners to observe the individual in different situations and to think about the evidence there is that the individual might have preferences for what has happened in each situation.

We plan to disseminate our project widely and we are setting up a project website where people will be able to sign up for updates.

We have had a huge response which is a good indication that this issue is something that people feel is very important. We are also, however, aware that we have sometimes contacted families and individuals who are already known to us. On balance, we felt that at this stage we needed to demonstrate what is possible and then, subject to funding, to support other organisations to consult much more widely with this important group.

Importantly, this project has shown that people with complex communication needs can communicate their views. To consult this group, professionals need to be more creative, flexible and plan the consultation further in advance. This all takes time, and should happen within a supportive communication partnership, including families and carers who are expert communication partners. If we can get consultations right for this important group, we can get them right for so many others.



The Seldom Heard project builds on existing good practice around listening to and involving people with severe and profound learning disabilities, including:

- *Supporting people with profound and multiple learning disabilities: core and essential service standards, Doukas et al (2017)*
<https://bit.ly/2SAcle9>
- *Mencap and BILD's 'Involve me' project – see the practical guide, evaluation and top tips summary* <https://bit.ly/2Uez5pR>
- *Mencap and PMLD's 'Raising our sights: Communication' how-to guide*
<https://bit.ly/3w6rlxY>
- *Communicating with people with the most complex needs: what works and why this is essential, Professor Juliet Goldbart*
<https://bit.ly/3hgkanc>
- *Communication as a human right, Sue Thurman, PMLD Link, Spring 2011*
<https://bit.ly/3y5ySnL>
- *'Valuing the Views of Children with a Learning Disability' and 'Stop, Look and Listen to me' are both available on CBF's webpage:*
<https://bit.ly/SeldomHeard>

If you do not have access to the internet, and want further information from any of the links supplied above, call us on 01634 838739.

Calling PBS Practitioners

We are looking for professionals who are passionate about PBS, want to introduce families and frontline staff to PBS and are able to co-deliver workshops with our Family Carer Trainers. CBF are recruiting new PBS Trainers to co-deliver our workshops on an occasional and freelance / casual worker basis. Please contact workshops@thecbf.org.uk to register your interest and find out how to apply to join.



Building positive relationships between families and the support workers supporting their relative

The CBF has teamed up with Paradigm UK to consider how to build and maintain positive relationships between families of individuals with learning disabilities and support workers or personal assistants who provide paid care and support for their relative.



The project purpose is to consider how relationships between families and support workers can flourish – when there are good relationships, what is it that is working well? When relationships are not so positive, what can be done practically to improve them? Building these positive relationships enables a better coordination of support, greater trust between families and support workers, and ultimately better support for the individual by bringing together all people involved.

We have collected views and stories through a short survey and in a workshop held between families and support workers. When these positive relationships do work, we have heard that honesty, clear routes of communication, key contacts and lines of referral, well-constructed and co-produced care plans, accountability, and addressing potential issues early-on have all contributed to relationships flourishing.

When these relationships are not so positive, we heard that there are often barriers relating to limited flexibility, lack of understanding about trauma, the prioritisation of routines, closed lines of communication and deferring to managers or overly strict guidelines/boundaries. These are just a selection of the topics raised, however most barriers consistently related to themes of involving

families, maintaining communications, and being honest.

We're interested in finding practical solutions to help these relationships to flourish everywhere. We have heard that there are acts and strategies that families, support workers, and managers/providers can take which help to build and strengthen these relationships. These can be things that initially appear small, such as telling families about the good things that happen through the day rather than only speaking of the issues that arise, or larger strategies, such as having a clear communication policy and encouraging co-production of care plans involving supervision and cooperation.



For the next stage of this project, work has begun to develop practical solutions to issues identified. What can we do to ensure good practice spreads, and to ensure that recurring barriers to positive relationships don't hinder support or lead to placement breakdowns?

This work is ongoing, and the next steps will include considering how we can engage people with learning disabilities in the discussions. The work has been made possible by Lottery funding.

If you have any thoughts on building positive relationships, or would like any information on work underway, please contact Liam:

liam@theCBF.org.uk or telephone 01634 838739.



We are currently recruiting Local Champion volunteers!

We're looking for family carers of children or adults with severe learning disabilities, who would like to:

- Learn information and skills to benefit your own family and others
- Help us reach families in your area who need CBF's information and support
- Use your free time to 'give back' and pass on your valuable knowledge

We need to fill these new and exciting roles:

Online volunteers: We will soon be launching our CBF Facebook Group, run by families for families. We need Facebook-savvy volunteers to help moderate the group to make it a safe and supportive space for our families.

If you are a family living in West Sussex, we need you to represent families of people with severe learning disabilities in your area: This unique role will involve representing the CBF at events and joining local discussions to ensure that your family member and others like them are considered and provided for locally. You'll have the support of the CBF and an opportunity to make a real difference to local policy.

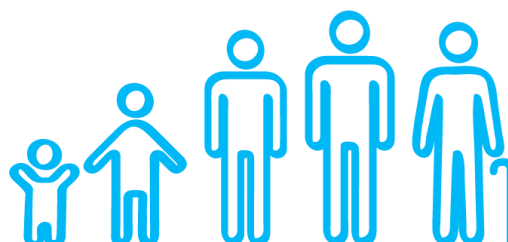
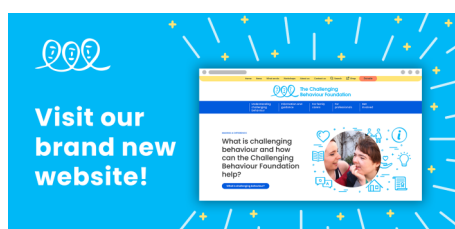
Other Local Champion roles are also available. Please note that no experience is necessary and online training will be given. If you are interested, send us an email: volunteering@thecbf.org.uk or call the Family Support Service on 0300 666 0126.

Resources accompanying the printed edition of this newsletter

Thanks to Government funding, the CBF is pleased to be able to send out printed copies of a selection of our resources with this newsletter. See the list below. Please also find enclosed a survey about family carer participation and a resource order form. We're aiming to get our resources to people who do not use the internet, so if you are able to download copies from our website please do pass these copies to families who could benefit from them.

For those of you receiving electronic versions of our newsletter, please click on the links below to read the resources:

- [Quick Read Challenging Behaviour Guide](#): this guide gives tips and strategies to help you and your family member during a period of new or increased challenging behaviour.
- The [Challenging Behaviour Charter](#): sets out the rights of the people with a learning disability and the action that needs to be taken.
- The [Medication Pathway for Family Carers](#) has been specially developed for family carers concerned about the use of psychotropic medication for their relative with a learning disability and/or autism. The first two sections are included in the printed resource along with a flyer to introduce the Pathway resource – the full version is available online and in print.
- [Making it happen](#): an information sheet for positively managing risk for children and adults with severe learning disabilities as we resume activities and face-to-face contact.
- [Family carer wellbeing and resilience](#): Resilience is important so it is useful to understand some of the steps you can take to achieve it.



Working in partnership

Family carer Pat is mother to Tinashe, who is an 11-year-old boy with a severe learning disability who is non-verbal and whose behaviour challenges.

Pat has had some very positive relationships with professionals, especially her health visitor Louise. For Pat, communication has played an important role in her working partnerships with early years' professionals. In this article, examples of good communication practice have been highlighted. The examples have been taken from a recorded interview between Pat and the CBF to give feedback to health visitors.



A friendly and caring attitude

Pat describes her early years' experiences with professionals as mostly positive, especially those with her specialist health visitor, Louise. Louise encouraged Pat to talk through the things that were worrying her and helped her undertake routine tasks like completing daily diaries, which had been a source of stress for Pat. Pat says of Louise "She was like a friend."

Reassurance is important

Louise and another specialist nurse helped Pat with sleep problems. The professionals were always clear that the problems Pat faced were to do with the needs of the child and were nothing to do with Pat's parenting. Although it became apparent that Tinashe's problems were more severe than Pat had first realised, it really helped to know that keeping Tinashe near to her at night and a lack of sleep training had not been the cause of the problems.

Easy access to integrated support

During the early years' Pat nearly always had

somebody with her, usually either her health visitor or her keyworker, Vickie. Because the two professionals worked in the same team, communication was easily facilitated – sometimes just involving a short walk across the building. As a result, Pat was able to get Tinashe into a nursery setting that suited him at a young age, despite him not being toilet trained and requiring special food.

The CAMHS-led PBS intervention undertaken by Dr Catherine Sholl meant that CAMHS brought the whole network of professionals together in supporting the family. Ultimately this prevented a family breakdown and a residential placement, enabling Tinashe to stay at home with his family.

Pat also talked about other aspects of communication which would be desirable in relationships with health visitors and other professionals:

Being non-judgemental and tolerant

Pat advocated for non-judgmental communication, which she felt was important in creating positive interactions between professionals and her family, and for ultimately ensuring that the services provided are really good. However, at times she also felt it was possible for parenting to be "blamed". She felt tolerance is needed for first-time parents who don't always have in place the knowledge or support they need.

Personalisation and being respectful

Pat is also aware of how we are all very different, with diverse backgrounds, so a person-centred approach is key to success. There will always be differences of opinion, but it is possible to find ways of working in these situations if both parties are respectful. Pat also said that when she is speaking, she needs to feel like she is being listened to and that she is not part of a 'tick-box exercise'.

We need to learn as we go along, but also to stay in touch

Pat felt that sometimes professionals who work with families don't like to admit their limitations. She felt there was absolutely nothing wrong with saying to a parent "I am not sure about his. Let me get back to you". Louise signposted Pat to a specialist nurse at CAMHS to resolve Tinashe's sleep issues, but importantly Louise remained in contact with the family. So, in the event of signposting, the person who does the signposting should still keep in communication.

Continued.....

Working in partnership (continued)

Working together requires valuing personal experience

Pat felt it is important for professionals to acknowledge expertise gained through experience. That way it becomes possible to collectively work together to get positive outcomes for children. She said: "Acknowledge me and acknowledge the expertise that comes from living with the child."



Open and frank conversations are good

Pat thought a frank and open conversation with the health visitor was important in the very first visit. Such a conversation should include an explanation of the role of the health visitor, and families should also be asked to think about, and define, how they want to be helped.



Pat admits that she has been lucky to have had one of the best experiences of early years' support, especially with her health visitor.

Unfortunately, not everyone has the same positive outcomes. If you want to find out more about improving or creating positive working relationships, you can look on our website:

www.challengingbehaviour.org.uk/what-we-do/sharing-best-practice

or call us on 01634 838739 if you don't have on-line access.

The CBF's peer support calls

The CBF is piloting support calls from a fellow family carer.

Sometimes it helps to 'offload' to someone who understands what you are going through. Our peer support calls are purely a 'listening ear', giving you the time to talk. The support is non-judgmental and confidential. This is not a counselling, information or advice service.

You will be offered 1 or 2 calls with the same family carer supporter. You are welcome to also use the CBF's other support before, during and after.

Open to parents, siblings or other close relatives of children, young people or adults with severe learning disabilities who display behaviour that challenges. We are currently piloting this service, if we are unable to offer you a Listening Ear call we will tell you about other ways of getting support.

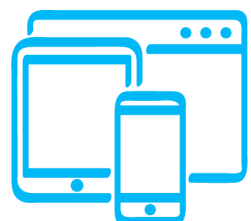
How to book a call

Please contact Elissia on 0300 666 0126 or support@thecbf.org.uk

More information about peer support

Find out more about Carers' Catch Ups and the Family Carers' Email Network:

www.challengingbehaviour.org.uk/for-family-carers/peer-support



Having choices and communicating preferences

In this article, Elissia Evans, the CBF's Family Support Triage Officer, gives practical insight into some of the ideas and technologies she's tried to aid communicating with her daughter.

As a parent of a non verbal child with severe learning disabilities, I've always been keen to explore ways in which my daughter, M, could communicate. In my opinion, one of the most important things in life is having choices and being able to communicate preferences.

When it became clear that it was unlikely that M would form speech, whilst I never stopped speaking to her, and mimicking her sounds, I began working closely with the SALT (Speech and Language Team), and basic Makaton was introduced into our everyday lives. Makaton is a unique language programme that uses symbols, signs and speech to enable people to communicate. However, due to M's inability to purposely control her hand and arms, I realised that it would be very difficult for her to ever be able to form signs. We had also introduced PECS (Picture Exchange Control System), and used the symbol cards at snack times, and to indicate when stopping/changing activities. In conjunction we also used talking tiles, which are small touch activated buttons you can record yourself saying words on. We use just 2 so she can press during meal times to indicate whether she wants 'food' or 'drink'.

I was offered a short course in AAC (alternative and augmentative communication – also known as an eye gaze system), and whilst I wasn't sure that she would grasp it, I attended and arranged a free loan of an AAC system. This was a great way to allow M the opportunity to explore another avenue of communication. Unfortunately, despite our best efforts, M didn't respond to it, but it brought me great comfort just knowing we'd been able to give her that experience.

Whilst we may not have been all that successful, as yet, in finding a way for her to communicate extensively, we do what we can to give her as many options as possible. This applies in doing everyday ordinary things, such as giving her the freedom to choose her own snacks, her cereal, the books we read to her – even which shower gel she'd prefer! Whichever item she looks at for any



great length of time, we reinforce her choice by giving her it – or she just reaches out and swipes it!

The journey family carers take when exploring ways to help progress, or aid, a child's communication, can be a long, frustrating and exhausting one. Professionals are not always reliable, and it often involves a lot of research and 'self learning', but the rewards can be great – even the 'little wins' are actually huge. It's so hard when your child has such complex needs to know what to tackle or prioritise. Just knowing that you're doing **YOUR** best, which will often differ from one person to the next depending on personal circumstances, is good enough.

Elissia, mother of M

CBF's Carers' Catch Ups



Carers' Catch Ups are friendly and informal Zoom calls for families to share successes and support one another. If you have a relative with a severe learning disability and want to chat with people that understand the challenges you may be facing, email: network@theCBF.org.uk to register your place now! If you don't have internet access, find out more about our new peer-to-peer telephone listening ear service by calling 0300 666 0126.

Your question from the email network

My son, who is going to be 18 in the middle of February, has been placed into an assisted living place with six other young people by the council. I want to know the legal things. He claims PIP (Personal Independence Payment). What will happen to the PIP if we stop? Also as parents do we have to buy all the things like clothes and toiletries every month? The residential placement is near to us. Who will be his appointed guardian for these benefits? Can anybody help me to understand these things please?

(1) If you are your son's appointee with the DWP continue to do so as I am sure he/you will have to pay for clothing, footwear, toiletries, barbers, activities and social events.

(3) You need to contact the DWP and become an appointee for his benefits. It's pretty straightforward. Also, if he has any money in savings in his own name, you can't touch it unless you obtain financial deputyship from the court of protection (see government website). You should not have to pay for things for him, as he's 18 and legally an adult so no longer your responsibility. Is he still in education? He may be able to claim ESA, or Universal Credit. My son will be 18 next week and gets PIP and UC. Good luck .

(5) If your son goes into Supported Living and has his own tenancy he can still get PIP. If he lives alone and nobody receives Carers Allowance he should get the Severe Disability Premium with his ESA (Employment and Support Allowance). He should also be able to claim Housing Benefit and be exempt from Council Tax if he is severely mentally impaired. Otherwise he can claim Council Tax Support (this is usually done with Housing Benefit) - claimed via Local Council.

If he is in residential care you usually do not get PIP. My son gets it for the weekends he spends at home. It is called "Boarders Allowance". Claim it retrospectively.

If you have appointeeship for his DWP (Department for Work and Pensions) benefits you can continue with this. Your local authority may do a financial assessment to assess how much he should contribute to his Social Care costs.

My son is in residential, so he is only left with £25.80 per week pocket money. This goes on petrol for his Motability Car. He is not funded for support with clothes, we buy those. The residential service provide toiletries etc, though many of his are on prescription. In supported living he will have to buy his own.

(7) Your social worker should be able to help you with your questions, otherwise try contacting your local carers centre.

(2) My son has two experiences of assisted living. He once shared with another young man in a house with one member of staff on duty 24/7. When this broke down due to my son's aggression he moved into his own flat.

He has a tenancy and claims housing and council tax benefits. I am his appointee so control his finances. He claims ESA and PIP. I pay housekeeping into a separate account from my son's bank for staff to use. They ask me for anything he needs like a new bed etc. He has to pay monthly towards his care, but this isn't a lot. He has a very good quality of life.

(4) When my daughter turned 18 we did not know she was entitled to claim Universal Credit - she received PIP for a vehicle but I was not aware until a few years later she was also entitled to Universal Credit.

I completed an application online for her and she was awarded the benefit within 2 months - and then this was further increased given her disabilities. I wished I had known sooner she was entitled to this benefit as it is very expensive trying to pay for everything yourself.

(6) RE:(5) You still get the mobility component of PIP if you are in residential care. Unlike the personal care part of PIP, the mobility component cannot be taken into account when deciding, for eg, how much your child should contribute towards the cost of the care package. We use the mobility PIP to fund a Motability car, but you can opt to use the money however you think best for your child.

Re the £25.80 'pocket money' that you're left with after the funding authority have taken their cut from ESA: I challenged this a couple of years ago, successfully. I argued that this money was all my daughter had left and had to cover all her activities, outings, clothes, books, toys (which need replacing regularly), and it didn't even cover her Riding for the Disabled sessions! I had to provide a year's worth of bank statements/receipts, including evidence of what we'd paid for her out of our own money.



I eventually got her care contribution reduced; the authority now take approx. 60% of her ESA, rather than around 80%; not a massive decrease, but it makes a significant difference to her over the year.

Practical communications resources for families and practitioners

Here at the CBF we welcome occasions to work with others who are supporting families. Recently we had the wonderful opportunity to work with the Institute of Health Visiting (iHV) on their Least Restrictive Practice: Understanding Behaviour project. The project aimed to raise health visitors' awareness of restrictive practices, how to challenge them and how to implement evidence-based alternatives. By working with families, we supported the iHV to develop practical resources and presentations which were shared with health visitors through a series of workshops and webinars.

In one of our workshops, we presented some examples of tools which can be helpful to support communication. One of these is a 'Now and next' board:

- 'Now and next' boards are resources that are useful for people who may struggle to communicate and understand what is being said, or forget what has been said. They can be helpful for people who struggle to move from one activity to another or become distressed when they do not know what is going to happen next or what the structure of their day is.
- They are essentially a shortened version of a visual timetable when it is more helpful for the person to have a short piece of information at that time.
- Now and next boards are split into two sections (now and next) and use detachable pictures that represent a part of the day to help people move from one thing to the next.
- The part of the day the person is currently engaged in (such as breakfast) is placed in the Now section whilst the part the person is doing next is placed in the Next section (in this example get school bag).
- The pictures should be something that is clear to the person. In our example we have used photographs but if the individual prefers using a board maker or objects of reference these should be used.

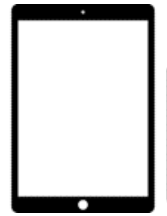
Now	Next
	

Article is continued on the next page.....

Practical communications resources for families and practitioners - continued

We then gave an example of how to break down an activity into visual steps. Here we showed how each step of “getting your school bag” could be represented.

Getting school bag ready



In this example, to get their school bag ready, the individual needs to place their book, pencil case, iPad and water bottle into their school bag. Each of these items are represented with a separate visual cue, which breaks the task down into smaller steps.

There are several ways visual supports can be used to support communication, help with completing tasks, make choices and promote independence. More example of these can be found on the National Autistic Society's webpage on communication:

www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/visual-

Another practical resource

Five good communication standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings



This paper introduces ‘five good communication standards’ for best practice. These will ensure reasonable adjustments are made to meet the speech, language and communication needs of individuals with learning disabilities or autism in specialist hospital and residential settings. The standards can be found at this link:

www.rcslt.org/wp-content/uploads/media/Project/RCSLT/good-comm-standards.pdf

The Autism and Intellectual Disabilities Intensive Intervention Team

In this article, Dr Catherine Sholl, Consultant Clinical Psychologist and Team Lead, at AID-IIT, tells us about her new specialist team in London.

The Autism and Intellectual Disabilities Intensive Intervention Team (AID-IIT) is a new national and specialist outpatient CAMHS team covering London. We are based within SLAM NHS Trust working closely with the Service for Complex Autism and Associated Neurodevelopmental Disorders (SCAAND). AID-IIT is funded by NHS England and was developed in the context of a lack of progress being made for children and young people under the Transforming Care (now LDA) Programme. Our aim is to **reduce or prevent where possible inpatient CAMHS admissions for children and young people with Intellectual Disabilities and Autism** and to support young people to continue to live within the community.

AID-IIT is a multi-disciplinary team including:

- Clinical Psychologists
- Consultant Psychiatrists
- Assistant Psychologists
- Occupational Therapists
- Speech and Language Therapist
- Clinical Nurse Specialist
- Specialist Teacher



Who can be referred to AID-IIT?

A young person's CAMHS professional can refer to AID-IIT providing they meet all of the following criteria:

- Under age 18
- Diagnosis of Autism or Intellectual/Learning disability
- Home address in a London borough
- Open to a London borough CAMHS who will remain active in joint working with AID-IIT
- Be:
 - ◆ At imminent risk of admission to an inpatient unit
 - ◆ Already admitted to an inpatient unit or
 - ◆ Recently discharged from an inpatient unit and there is a concern about risk of re-admission.

What can AID-IIT offer?

AID-IIT will work jointly with local services for a short term but intensive period, offering a range of activities depending on the young person, family and local network's needs including:

- Complex multi-disciplinary assessment of the young person's needs and recommendations for their support
- Short term multi-disciplinary interventions for the young person and their family
- Consultation, training and advice to other professionals
- Attendance at care planning meetings (e.g. CETR, CPA)

The team offer an outreach approach, working with young people wherever they need to be seen e.g. in their homes, inpatient units, school, community settings.

More information



Email: AIDIIT@slam.nhs.uk

Website: <https://www.slam.nhs.uk/national-services/child-and-adolescent-services/autism-and-intellectual-disability-intensive-intervention-team/>

Dr Catherine Sholl

Consultant Clinical Psychologist and Team Lead, AID-IIT

Family carers: not online? Here's what CBF offers...



You don't need the internet or email to contact the CBF. Here is a look at what we offer for families who are not online or find it hard to communicate via emails and websites. Please read the accompanying flyer about how to get involved in our work, or see:

<https://www.challengingbehaviour.org.uk/get-involved/>



Call us using an interpreter

Family carers whose first language is not English can speak to us on the phone via an interpreter, free and in confidence.

Please call us to arrange this for you or a friend/ relative.



You can call the

Family Support line

on **0300 666 0126**

9am-5pm Mon-Thur
9am-3pm on a Friday

(calls cost the local rate from landlines and most mobiles)

We offer non-judgemental, confidential support.

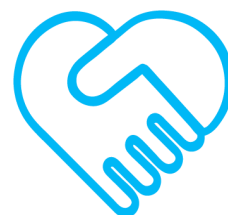
Peer support calls

Sometimes it helps to 'offload' to someone who understands what you are going through. These calls offer a listening ear, giving you the time to talk confidentially. This is not a counselling, information or advice service.

We are currently piloting this service, if we are unable to offer you a Listening Ear call we will tell you about other ways of getting support.



Our range of information sheets and DVDs are free of charge to family carers in the UK and can be ordered by calling 01634 838739.



CBF aims to support families who care for a child or adult with a severe learning disability whose behaviour challenges. A **severe learning disability** usually means a person has very limited or no verbal communication, and requires a lot of support to complete everyday tasks. Please note as a small charity with limited resources we are unable to offer support to those who are experiencing challenging behaviour associated with mild / moderate learning disabilities.

Marathons and half-marathons!

Keith Ridge, the Chief Pharmaceutical Officer for England, is running the London Landmarks Half Marathon on 1 August : <https://uk.virginmoneygiving.com/KeithRidge1>

The CBF's very own Carina Down is running the 2021 London Marathon on 3 October: <https://uk.virginmoneygiving.com/CarinaDown2>

If you want to support these efforts, but cannot contribute on-line, call us on 01634 838739.

Thanks to everyone — sporting heroes and supporters alike.



Donations to the CBF

A big thank you to all those who support us with regular and one off donations through Virgin Money Giving, direct debits to our bank, or cheques sent to our address (see footer).

www.challengingbehaviour.org.uk/donate

If you would like to donate but do not have internet access, please give us a call on: 01634 838739 for details.

To donate by text: Text **CBF** to 70450 to Donate £3. To donate more simply text CBF followed by the amount you wish to donate. i.e. **CBF 10** to donate £10.

Also, thank you to those taking advantage of fundraising for free, by using Amazon Smile, Everyclick, Give as you Live and Easy Fundraising when doing their online shopping. It really does make a difference! and we're grateful for your support.



Don't forget the CBF100 Club!

For £12 per year you will be entered into a monthly draw with the chance to win £25 each month or £50 in November. More info here:

www.challengingbehaviour.org.uk/donate

Why not purchase a number, or two, as a special present for friends and family? To sign up please email:

info@thecbf.org.uk

or call us: 01634 838739.



Support and funding at the CBF

During the COVID-19 pandemic it is more important than ever to support each other and we encourage family and friends to keep in touch remotely. Our Carers' Catch Ups (see page 10) are still being held, and we're piloting a listening ear service (see page 9). We also continue to connect by email to people in similar situations, providing some additional comfort, advice and support. See www.challengingbehaviour.org.uk/for-family-carers/peer-support for more information.

Our family support line is still open 5 days a week to support families — you can call us on: 0300 666 0126. We are continually producing new resources and following the latest guidance to inform families.

We rely on donations, grants and fundraising to continue our work helping families. Find out how you can help us at: www.challengingbehaviour.org.uk/get-involved or telephone 01634 838739.

For the printing and distribution of this edition of Challenge, and the accompanying printed resources, the CBF secured Government funding. It is important that we provide a range of accessible information and support in different formats for families during this difficult time, including printed copies delivered directly to people's homes. If you know somebody who wants to be added to the mailing list for future printed newsletters (subject to funding) please call us on 01634 838739.

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.