

# Challenge



making a difference  
to the lives of people with  
severe learning disabilities

Spring 2017

The newsletter of the Challenging Behaviour Foundation

## Checking Up on Health

### We all matter, so why do we allow people with a learning disability to die young?

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*Results from our consultation on CAHMS Tier 4 services, a round-up of mental health policy, and mental health for family carers*

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*A round up of what's been happening, and what's new on the web.*

'Challenge' is the newsletter of the Challenging Behaviour Foundation, supporting those caring for individuals with severe learning disabilities whose behaviour is described as challenging

Like many fathers I look at my three children and wonder what their futures hold. I want them to be happy, I want them to wisely choose their life partners, careers, pastimes. I want them to live life to their fullest potential...and I want this equally for all of them. They all matter.

My eldest child has a learning disability and needs constant care and support. She matters too...and equally to the others. She can't tell us verbally when she is ill... but she does tell us, through a range of non-verbal communications we have learnt over many years. Health professionals will never know this language as we do, so our opinions as family members become extremely important. However, my experience is that family carers are often not treated as experts. Instead we have to battle to avoid health needs being overlooked.

Part of the problem is that our society views learning disability and autism as diseases. They have been 'medicalised'. Healthcare professionals begin to see only the disability and miss other important issues. I would encourage everyone to challenge the term 'diagnosed with a learning disability'... which only serves to medicalise further.

Detailed information from organisations like Public Health England and NHS Digital is now showing us the extent of health inequalities. There is more morbid obesity, poorer-uptake of cancer screening programmes, and further confirmation that people with learning disability are dying 15-20 years prematurely from preventable causes.

But things are changing. The National Diabetes Audit recently reported care of people with learning disability who have diabetes is actually better than for the general population. This month, GPs will



Dominic Slowie

have additional incentives to offer high-quality annual health checks for adults and adolescents with a learning disability, and people of all ages are already entitled to and receiving free flu immunisations. Soon all deaths of people with learning disability will be reviewed as part of the emerging Learning Disabilities Mortality Review and Learning From Deaths programmes.

However, evidence suggests tackling health inequality also requires us to understand and address social factors. A research team at University College London is currently working to investigate impacts of these on people with learning disability. In particular, they are looking at how other countries address social issues to see if there is anything we in the UK can learn.

Change is often slower than I and others wish, but clear vision, persistence and relentless determination will deliver, and has to... because we all matter.

#### • Dominic Slowie

*National Clinical Advisor (Learning Disability & Premature Mortality) and was National Clinical Director for Learning Disability 2013-2016.*

## Your Comments

With recent evidence showing low-uptake of GP annual health checks for people with a learning disability, we wanted to know what stopped you from attending. We asked our followers on Facebook and Twitter, "What, if any, were the barriers you have faced getting your loved-one to a health check-up?"

Here are some of the comments we received:

Tried to arrange one about a year ago after hearing about them through school. My GP surgery refused. Told me they were not obliged to offer these.

Getting to the doctor is very stressful. It's a new doctor every time and I have to explain all about my son's condition before I even start! They make us wait for so long, by the time we get in he won't let the doctor near him! I avoid it unless we have to go.

The receptionist at my daughter's GP surgery did not know what I was talking about. I suggested she double check that this surgery did do health checks and they did. But there has never been a request for a follow-up. I will ring the surgery again to go through the same procedure.

We have had these for my twins. On our last visit the nurse actually suggested it might be better to do a home visit as the girls would be more comfortable being seen in familiar surroundings. Well done our surgery for using initiative and supporting what's best for my lovely young ladies.

Thank you for all your comments!

If you'd like to feature in this column we'd love to hear from you. Look out for our posts on

 facebook.com/theCBF and  
 @cbfdn,

or send your comments to  
communications@theCBF.org.uk.

# Health, Hope and Happiness



*Vivien Cooper*

If you ask people what is important, most will say they want to be happy, and they want good health. Our mental and physical health impacts on everything we do – and of course this applies to people with learning disabilities too. The difference is often they are not able to tell us in words how they feel, and so we all have a responsibility to find other ways to make sure people with learning disabilities have the same opportunities for good health as we do. We know there are huge health inequalities and we have to make the system work much better. There are many ways this is starting to happen- from having learning disability liaison nurses in hospitals, to regular healthchecks, and more accessible health screening processes which provide hope for improvement.

But there is still some way to go. And it is not straightforward. We know there is a strong link between physical health and behaviour – if a new challenging behaviour emerges, it is essential to get a physical health check to rule out a physical cause. Increased headbanging may be due to an ear infection, or toothache. Increased aggressive behaviour may be due to pain. Equally a person may not be "their usual self". My son is subdued (as opposed to quite lively!) when unwell – and there can be assumptions made by health professionals: "Well he is sitting there quite calmly so he is probably OK" – when the reality is if he was OK there is

no way he would be sitting still! Regular healthchecks, including dental checks, can reveal otherwise "hidden" issues. A recent routine dental check under general anaesthetic revealed my son had an abscess and severe infection – he would have been in a lot of pain and yet we were completely unaware.

At the CBF many families who contact us describe cocktails of medication their relatives have been prescribed, often with no significant benefit and with serious side effects. There remains a medicalization of behaviour – despite the NICE guidance clearly stating to "consider antipsychotic medication to manage behaviour... only if psychological or other interventions alone do not produce change within an agreed time, treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour, or the risk to the person or others is very severe...".

A recent CBF survey of family carer's experiences on the use of medication revealed families needed accessible, timely and practical information about medication - potential benefits and disadvantages - as well as alternative approaches to medication. Often the medication was prescribed to address a symptom (living with people they didn't get on with, or being awake at night when there were no night staff) rather than addressing the underlying issue.

The recent Dispatches programme showed the stark contrast of the wrong kind of support in inpatient institutionalised services – and the life changing difference that the right support delivers. There is welcome talk of being "outcome focused" and it was clear from the documentary that having your basic human rights met (including health needs, and social and emotional needs) results in a fairly fundamental outcome – feeling happy. Children, young people and adults with learning disabilities who display behaviour described as challenging have the same rights as the rest of us to health, hope and happiness.

### **Vivien Cooper OBE**

*Chief Executive and Founder of the Challenging Behaviour Foundation*

# Checking up on Health

Everybody has an equal right to good healthcare, but unfortunately for people with a severe learning disability whose behaviours may challenge this can be difficult. It can often seem that these rights are not being upheld and that loved ones are not receiving the same level of healthcare as everybody else. In the family story on this page, Bernadette tells the shocking but all too familiar story of her son Adrian who suffered for three years with dental pain before getting the treatment he needed. It is clear that a concentrated focus on health of people with a learning disability is needed.

This spring edition of Challenge is 'Checking Up on Health'. We are looking at the major challenges that exist in accessing good healthcare for your relative and what can be done to address them.

Our lead article has been written by former National Clinical Director for Learning Disability at the NHS, Dr Dominic Slowie, himself a father of a child with severe learning disabilities. He talks about what he hopes the future of healthcare will be for his daughter and what he sees as an unhelpful 'medicalisation' of learning disability and autism.

Pages 4&5 look specifically at mental health. We begin with a review of results from the consultation we ran with family carers on inpatient mental health services for children & young people, and follow with a commentary by Norman Lamb MP on putting care back in the community. Much has been promised from the Government for changes in mental health policy but what, if anything, does it mean for people with learning disabilities? Jill Davies from the Learning Disability Foundation gives us an overview. Finally, your loved one's mental health is not all that needs protecting. Consultant psychiatrist Dr Sunil Raheja explains how families themselves can look after their mental health and try to avoid burnout.

Many people with a severe learning disability suffer unmet health needs. Pages 6&7 look at the reasons why and what we can do about it. The first article is a summary of research by the Learning Disability Carers Community on barriers to annual health checks. It is then followed up by a guide to protecting the health of your loved one. Family carer Lynne rounds off the section with a story of her experiences arranging reasonable adjustments.

*We hope you find the content of this newsletter useful. If you have any comments or other feedback, please email us at [communications@theCBF.org.uk](mailto:communications@theCBF.org.uk). If you would like to suggest a topic, or contribute an article to a future edition of 'Challenge', we would love to hear from you.*

## About us

We are the charity for people with severe learning disabilities who display challenging behaviour and those who support them. We make a difference to the lives of children and adults across the UK through:



Information



Supporting You



Workshops



Driving Change

Our vision is for all people with severe learning disabilities who display challenging behaviour to have the same life opportunities as everyone else and, with the right support, to live full and active lives in their community.

Our mission is to improve understanding of challenging behaviour, empower families with information and support, and help others to provide better services and more opportunities to people with severe learning disabilities who display challenging behaviour.

To access our information and support, or find out more about what we do, call **01634 838739**, email **[info@theCBF.org.uk](mailto:info@theCBF.org.uk)**, or visit our website: **[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)**.

## Dental Pains

My son Adrian is 36. He has a fantastic sense of humour and loves getting out and about. Adrian also has autism and a severe learning disability and until very recently he lived happily in his own house with 24/7 support.

This all changed when Adrian's wisdom tooth was taken out. From that day, he would always complain of tooth pain and ask to go to the dentist. His behaviour deteriorated and he was no longer the happy, contented man I knew.

The battle to get Adrian dental treatment took three years. Repeatedly, I was told by professionals there were no problems with Adrian's teeth and his complaints of pain were merely 'behavioural'. Support staff didn't believe Adrian's change in behaviour was pain related. They shouted at him, or sent him to bed for being 'naughty', which just made things so much worse. Last year, a neurologist diagnosed Adrian with nerve pain and prescribed a medication called Pregabalin. But this made his anxiety even worse, gave him blurred vision and incontinence. Things climaxed when Adrian's support provider withdrew without notice. With no alternatives, Adrian had to move from his 6-year home into temporary accommodation, miles from his family. I take him to visit his old house just so he understands it's still his and he'll be going back soon.

In October, Adrian finally received dental treatment. His mood and behaviour improved dramatically, but he continues to complain of occasional tooth pain. I showed Adrian's CT scan to my own dentist who suggested Adrian had a split bone in his jaw. I'm still fighting for this to be investigated further. Meanwhile, Adrian's house is nearly ready to move back into and hopefully a new support provider will be in place soon.

Recently I went through Adrian's staff communication book and copied down entries where Adrian complained of pain. My notes filled 28 A4 pages! If Adrian didn't have a learning disability I'm sure he wouldn't have had to wait three years for dental treatment he needed.

**Bernadette**  
*Adrian's Mum*

# Family Carer Views on Inpatient Mental Health Services

The CBF has been working with mental health charity Young Minds to find out what family carers think about inpatient Children and Adolescent Mental Health Services (Tier 4 CAHMS). This was done through a consultation looking at family carers' views of the service specification being developed to direct Tier 4 CAHMS inpatient learning disability services. These service specifications should explain to family carers exactly how their relative will be treated as an inpatient, however our results show that a majority of family carers find the specification hard to follow and many have concerns surrounding the level of care they could expect for their relative.

Nobody responding to the survey thought any part of the specification was 'completely clear' and in most areas the reverse was true. Referring to a relative, one family carer expressed concern that it sounded like "it would be very hard for him to get the support he needs" while another respondent simply commented the specification was "too complicated".

The service specification often mentioned 'involving families where appropriate' in their relative's care. This was rated as especially unclear by family carers with 60% marking it as 'not clear at all'. One family carer said "I believe it should always be appropriate to involve family and work in partnership" whilst

another said the word 'appropriate' was too "open to interpretation". One family carer referred to the specification as "a type of dictatorship from above, by professionals."

Other concerns about the service specification included the limited guidance on use of PBS or other alternatives to restrictive practices. One respondent said Tier 4 CAHMS should involve "no use of force and restraining methods, either physically, by seclusion or overuse of medication." Another stressed using "methods other than medications such as PBS and CBT". Many family carers thought discharge planning should begin from the time of admission, involving both families and the young person. It is important "that discharge to a new residency is identified early on and a gradual step by step programme is agreed on for transfer" said one family carer.

The consultation has led to a number of recommendations, for example making the service specification clear and useable for family carers, greater use of evidence-based practices such as PBS, and a greater focus on discharge planning. A copy of our report will be sent to NHS England and we hope they will take the feedback on board when finalising the Tier 4 CAHMS service specification for family carers.

## Putting Care Back in the Community



Norman Lamb

When I was a Health Minister, one of my most important goals was to improve the lives of people with learning disabilities and autism whose behaviours may challenge.

These people have a right to lead their life like anyone else. They have a

right to live as part of their own community – to have a social life, opportunities to work where possible, and to be treated with the same dignity and respect that other people would expect.

But we know that this is not always the reality. Too many people end up being admitted to hospital – where they often stay for months, even years. And too many people get treated dreadfully in these places, like second class citizens.

I vividly remember meeting Fauzia, a young woman with autism who I visited at a large hospital in Northampton. She was regularly restrained, and was also put into seclusion in a room which was more like a prison cell. It was one of the most horrifying things I have witnessed. And the real scandal is that this happens to thousands of people across the country.

Determined to fight this injustice and ensure better lives, we set a new ambition of getting people out of hospitals and supporting them in the community. We also proposed giving individuals and their families the legal power to challenge decisions about how and where they are cared for, and more control over how the money available for their care is spent.

But progress has been horribly slow. Thousands of people are still stuck in big institutions. The new legal rights I proposed have not yet been introduced. And many people still do not enjoy the personal budgets they should be entitled to.

There is a moral duty to invest more in community care so that people like Fauzia can live full and fulfilling lives. Since she left the hospital, she is flourishing and has not been restrained once. But so far, the Government has failed to do this. My fear now is that politicians are spending too much time thinking about Brexit and not enough time making sure that everyone with illness or disability – including a learning disability – gets the care they deserve.

But thanks to recent media interest, people are talking about learning disabilities and challenging behaviour. People all over the country have been contacting me to share heart-breaking stories about the shocking treatment of their loved ones. So now is the time to act. We have to seize the moment and bring an end to this injustice.

### Norman Lamb MP

*Liberal Democrat Member of Parliament for North Norfolk and former Health Minister*

# What's Happening in Mental Health Policy?

In January, Prime Minister Theresa May outlined her vision for a 'shared society', unveiling new plans for removing the 'hidden injustices' faced by people experiencing mental ill health. Several new measures to address this were proposed including mental health first aid in all secondary schools, more support for people in the workplace, and £15 million to be spent on community care.

Whilst it was good to hear the Prime Minister put mental health on the agenda, it is unclear if any of these plans will have an impact on people with more severe learning disabilities. Numerous policies and initiatives have been published during the past few years, for example; the 'No health without mental health' strategy which called for an equal status of both mental and physical health and the Children and Young People's Mental Health and Well-Being task force. Whilst some of these support people with learning disabilities, for example the roll-out of Improving Access to Psychological Therapies, and the Liaison and Diversion services for those engaged with the criminal justice system, little appears to be addressing those with more severe and complex needs.

So, what is available for people with more complex needs? The Transforming Care Programme is developing new models of care

which include providing more choice for people and their families, and more say in their care; providing more intensive support for those who need it, so that people can stay close to home; and for those that do need inpatient care, ensuring it is only for as long as they need it.

We need to remind commissioners and service providers about the 'No health without mental health' strategy which underlines the importance of providing equal access to services for everyone, as well as to demonstrate compliance with the Equality Act and Mental Capacity Act.

Finally, we must use the new NICE guidance on mental health problems in people with a learning disability as a lever to ensure that annual health checks now include mental health assessments. One practical way to address this is to support people or their family carers to monitor mental health prior to the appointment and to remind GPs about their duty to check-up on mental health needs.

**Jill Davies**

*Former programme manager at the Foundation for People with Learning Disabilities*

## Burnout



*Dr. Sunil Raheja is a consultant psychiatrist working in mental health and learning disability*

As a carer it is very important to ensure you take adequate time to take care of yourself. Otherwise there is significant risk of burnout. I can speak from personal experience in my own life. None of us are immune and it is important to realise the warning signs and take pre-emptive action. What is burnout?

Burnout is a state of chronic stress. It builds up over time and leads to:

- Both physical and emotional exhaustion
- Negative feelings and detachment
- Feelings of uselessness and lack of achievement

So, what have I learnt that can protect against burnout?

- 1 **The importance of adequate rest. Sleep is really important.** Most of us need 7-8 hours at least but this can be very difficult for carers who have disturbed nights. When you are tired it is easier to feel discouraged and overwhelmed. Rest is also important for ensuring you have time to switch off.

- 2 **Don't over-commit yourself. I have been often quick to take on more and more activities without ensuring there is adequate time to stop and recharge.** There is a tendency for us to over-estimate what we can do and carers in particular aim to achieve a lot for their relative. You may need to pace yourself and take on one aim at a time.
- 3 **Ensure you do those things that re-energise you.** When life gets busier or stressful it is so easy to tell ourselves that we don't have time to do those things that rejuvenate us. In fact the opposite should be the case. So for me regular prayer and meditation, regular exercise and deep friendships are not optional extras. In stressful times, I rely on them even more.
- 4 **Go back to your foundations. Like physical pain in the body, feelings of burnout are pointing to a deeper problem.** What are the assumptions I am making about myself and my life? What am I trying to prove to myself or to others, or even God?
- 5 **Connect with safe people.** There are people who lift us up and there are people who drain us. I am thankful to have safe friends to turn to when I feel overwhelmed and discouraged. It is in deep satisfying friendships that true contentment can be found. I love how someone has put it, that 'Friend power is much more powerful than willpower'.

To read Dr Sunil's full blog post, other posts and podcasts, go to: [www.dr.sunil.com](http://www.dr.sunil.com)

We understand that as family carers it can be difficult to find this extra time to relax and rejuvenate. The CBF's information resource 'The Impact of Caring on Families' provides more information and support for family carers going through stressful periods. Download it here: <http://bit.ly/2oZH60h>

## Health and Mental Health Information Sheets

Children and adults with learning disabilities are more likely to have physical and mental health problems than the general population. Our Health and Mental Health Information Sheets provide help and advice for keeping the person you care for mentally and physically well.

There are many reasons for health problems in children and adults with learning disabilities including illnesses associated with a specific syndrome like Down Syndrome, unhealthy lifestyles and difficulties diagnosing or treating health conditions. Meanwhile, chances of a person developing a mental health problem are elevated if the person has poor social support, low self-esteem or little control over their lives. Common physical illnesses are respiratory conditions, heart disease and cancer, while mental illnesses might include depression and anxiety disorders.

If an individual is in pain or experiencing mental health symptoms, they are more likely to display challenging behaviour. If this behaviour gets the child or adult what they need, they may be more likely to display it in the future. It is important to seek medical attention if the person you care for displays sudden changes in behaviour as this can indicate an underlying unmet health need.

Our information sheets on these topics will help you to spot the signs of ill-health and give you tips about what you can do to help the person you care for.

To download copies of the Health and Mental Health Information Sheets visit <http://bit.ly/2mSjLrn> and [http:// bit.ly/2n2Rwv2](http://bit.ly/2n2Rwv2)

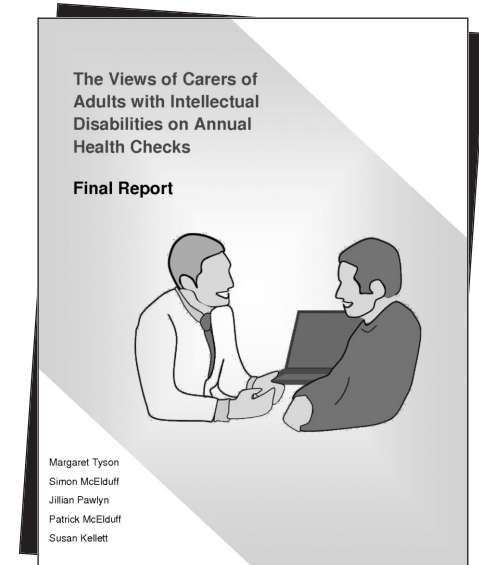
# Why Are Health Checks So Often Missed?

Recent evidence from NHS Digital shows people with learning disabilities have life expectancies much shorter than the general population. While there are many reasons for these lost years, the most significant is undoubtedly the number of undiagnosed and untreated health conditions. In 2009, concern grew so much over this, the Government decided to introduce a new incentive for GP surgeries to offer adults with a learning disability free annual health checks (AHCs). Despite this offer however, 2014 figures show only 44% of people who were entitled actually received their free health check. To understand why, Susan Kellett, founder of Learning Disability Carers Community and Margaret Tyson, researcher at Manchester University, decided to launch a survey of carers' experiences.

In total around 280 people responded through the yearlong online survey, to questions ranging from knowledge of AHCs, barriers experienced getting access to appointments, and confidence in quality of the check itself. The results begin to paint a picture of just why uptake is so low.

A worrying 82% of family carers had not even been informed about the availability of AHCs for their relative. For most, this was because they had not received an invitation letter. One family carer explained, "the onus is placed on the carer...to organise it". Many others, meanwhile, were simply unaware that AHCs existed at all. Some family carers appeared reluctant to take their relative to an AHC because of confusion about the purpose. For example, several family carers pointed out since their relative saw other clinical specialists, their health was being suitably well-managed. Others preferred to arrange to see doctors only in times of ill-health.

Further barriers were reported by a significant number of family carers who were turned away by GPs claiming insufficient resources to run AHCs. GP surgeries often lacked the skills to deal



*The Views of Carers of Adults with Intellectual Disabilities on Annual Health Checks Report*

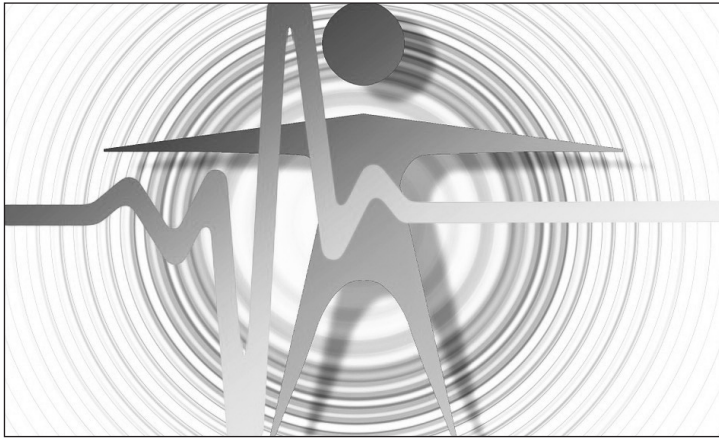
with challenging behaviour and offered few reasonable adjustments in return that have left many simply unable to attend.

Further questions revealed that important checks were often missed during AHCs and satisfaction with quality significantly dropped when family carers became aware of this. Breast, testicle and cervical smear examinations were rare, and clinicians frequently neglected to run blood or urine tests, or to assess sight or hearing problems. Carers also reported dissatisfaction with the clinician's approach and one carer noted that the AHC "seemed to be a bother for the nurse".

Better advertising or promotion of health checks was a key recommendation of the survey. Many carers also requested guidance on what to expect from AHCs whilst others stressed that their provision should be compulsory. Ultimately, the aim of the AHC is to move from reactionary healthcare to health protection and this research stresses that this is what needs to happen on the ground.

To download the full report visit: <http://bit.ly/2n2DUjz>

# What Can You Do To Help Meet Health Needs?



Health inequalities for people with a learning disability are well-known to relevant authorities, but a startling number of people still face problems getting their health needs met. With a recent survey finding three out of four people with a learning disability and behaviour described as challenging can be diagnosed with an unmet health need (from acid reflux to more serious diseases like heart disease and cancer), reducing health barriers has become paramount.

One problem faced by carers is that symptoms of physical ill health can be difficult to recognise especially if the person has limited communication. The idea that increasing episodes of challenging behaviour could be attributable to a physical health problem is often missed, but considering an undiagnosed health complaint should be priority. Often, a GP appointment will help reassure and rule out health problems; other times, minor health problems, such as an ear infection can be identified - with treatment having positive effects on challenging behaviour.

But as well as reacting when the person is distressed, it's equally important to maintain a healthy lifestyle. Reduce infections by making sure personal hygiene tasks are carried out, and minimise risk of more serious illness by supporting healthy eating and physical activity.

## Family Perspectives – Reasonable Adjustments

*Lynne and Luke are mother and brother of Chris, a young man with severe learning disabilities and autism. Chris has complex support needs, so needs a lot of 'reasonable adjustments' under the Equality Act 2010 to access healthcare. In this article Lynne and Luke describe Chris' hospital admission planning.*

Chris has an individualised Health and Wellbeing passport, which describes what he needs to keep healthy and what to do when he is unwell. He has had reasonable adjustments made to his healthcare, such as regularly using 'urine multi sticks' to test for abnormalities in various functions. However, there has also been uncertainty and confusion about how to assess Chris' health, as he is fearful of human contact. After a difficult experience at a planned hospital appointment, we knew we needed a detailed plan for any hospital admissions.

An Individual Care Management Plan was drawn up for Chris, coordinated by the GP and involving his family, support provider and CCG. The document lists his patient details, why the plan is needed, his background medical history, the names and contact details of key people involved in his care. The plan for Chris to be taken into hospital includes adjustments such as:

Another way to protect the health of adults in your care is to attend an annual health check (AHC). Available at many GP surgeries, these checks aim to diagnose ill-health as early as possible. You have a right to reasonable adjustments to make appointments easier such as going at quieter times, booking double appointments, or even taking the person you care for early so they can familiarise themselves with the environment before any medical tests.

"The Cardiff Health Check" is the procedure recommended by the Royal College of General Practitioners for AHCs. GPs or nurses following this guidance should do the following:

- A round of general health checks, including taking height, weight and blood pressure, analysing urine and a cervical smear and breast examination for women. A blood test can also be done to check levels of cholesterol, blood sugar or other body functions.
- Ask about abnormal symptoms. For example, whether the person has been constipated or suffered a long-term cough.
- Ask about escalations in challenging behaviour.
- A thorough physical examination (e.g. of heart, lungs, digestive system) and also of changes in ability to see, hear, communicate and get around.
- Review prescribed medications for effectiveness and side-effects.

After the health check, the GP should produce a summary and action plan. These should be sent to the person's family and/or support provider to follow.

If you are at all worried about health checks for the person you support, contact the surgery to see what reasonable adjustments are available. If annual health checks are not offered, your Clinical Commissioning Group should have alternatives in place to ensure health monitoring.

- Ambulance staff will telephone ahead to A&E.
- A private room will be ready for Chris, with low arousal environment and no small objects.
- Hospital staff on stand-by, including A&E consultant, senior nurse and an anaesthetist.
- The sedatives and anaesthetic he should be given.
- Chris will be accompanied by support staff and family at all times.

Should Chris fall ill or injure himself, his support staff, paramedics and hospital staff would follow this plan to ensure the necessary adjustments are made for him to access the healthcare he needs.

Family and the support provider had to be proactive to bring this plan together and the professionals involved needed to take a holistic view of Chris' health, work together and be creative. It took considerable time and effort, but it has made a huge difference to Chris's wellbeing.

**Lynne**, family carer

## Planning for the Future: Information Pack

We are frequently contacted by family carers expressing concerns about the availability of good local support for their loved-ones at times of transition, whether from children's to adult services, out-of-area placements back into the community or one provider to another. Sometimes, it can seem that nowhere offers the right support to fit your loved-one's needs. The key is to start thinking about different options early, and to plan for the future.

But thinking about the future can feel very daunting for family carers who often don't know where to find information and support. Our newly updated Planning for the Future (England) Pack has been designed in partnership with families to deliver practical advice and guidance on planning for transition.

Planning what will happen after your child reaches adulthood must legally begin when they are 13-14 years old, but there is no time too early to be considering options. Your child's school should be key in organising transition meetings, attended by yourself, your child's headteacher and their social worker. They should focus on a person-centred approach by considering your child's preferences for the future.

There are many housing options for adults with a learning disability including residential carehomes, continued education and supported living, each with their own advantages and disadvantages. It is important that your child continues to have community access and is able to carry on doing things they enjoy.

Every person with social care and support needs is entitled to a personal budget which gives them or their family carers control over how needs are met. Funding to meet the health needs of your child from the NHS is also available. If your child has their own home you may receive a grant to adapt the home for their disability whilst benefits including employment, housing and disability benefits could also be claimed.

To read this information in more detail, please visit <http://www.challengingbehaviour.org.uk/education-housing-social-care/planning-for-the-future-pack.html> or email [info@thecbf.org.uk](mailto:info@thecbf.org.uk) to order your FREE copy.

### Q: Has anyone found any sources of funding for sensory integration therapy?

**A1:** I managed to get the Clinical Commissioning Group to fund Sensory Integration by approaching my solicitor with what had been identified as a need. Most parents will know that if it's been identified as a need then in law it MUST be met ... I would say many traditionally commissioned therapies including Sensory Integration have always been cited in NICE guidelines and it is quite specific about treatments and pathways

... With our children, as parents we need to take the time to research these issues because if you were to ask your consultant or social worker they would just tell you that the local authority or health authority doesn't do it, but that's very different - they can and should!!

Taking no for an answer is not an option...

**A2:** It is really worth trying the Skills for Care funding arrangements, especially if the Sensory Integration Therapy training is focused on carers/assistants/parents.

### Q: My 18 year old daughter completely refuses to cooperate with blood tests. Her doctors don't bother any more as they say it is easier to get a stool sample. I am worried she is missing out on medical tests. What can I do?

**A1:** Patients who are needle phobic at our local hospital are often supported by the acute liaison nurse, who discusses a mild sedative with the General Practitioner (GP) prior to coming in. Once there, the nurse has liaised with the anaesthetic team who often offer midazolam as a small drink or similar medication. This relaxes the person generally sufficiently enough to enable a general anaesthetic to be given or cannula inserted. People who regularly see our community dentist have as many procedures carried out as safely as possible in the acute setting. Good luck, and yes phlebotomists are generally much quicker as that is all they do and have built up the skills!

**A2:** I am currently dealing with exactly this problem for my 24-year-old daughter (SLD, autism, epilepsy, and challenging behaviour). She should have 6-monthly blood tests to check her drug levels, also there is a history of diabetes in my family and my daughter is overweight at the moment, so this needs to be checked

too. She refuses to allow blood to be taken, despite home visits by the district nurse and her GP.

I know this is a bit extreme, but she is shortly to have a general anaesthetic as a day case in hospital for a dental check-up. Whilst 'under', she will also have a wisdom tooth removed, and her GP has arranged for her to have an ECG and a blood test done. I have even managed to persuade the medical staff to let me in to cut her hair, as she hasn't allowed it to be washed or cut for several years. She will have light sedation at her residential home, so that we can get her into the hospital with the minimum of distress to her.

If this is not an option for you, conscious sedation – of the type some specialist dental clinics use, where the patient is not fully unconscious, but has no knowledge of what is happening and no memory of it afterwards – could be a possibility.

**A3:** Probably not much help but my 18 year old autistic son always gets bloods taken when he is under anaesthetic getting teeth worked on. This happens every three years or so and staff at the dentist are always very cooperative when requested by doctor to take bloods. Just a thought if your daughter was getting dental work done. Good luck!

*Recommendations for specific products in this article are made by people on our Email Network; inclusion doesn't constitute endorsement by the CBF. Readers are encouraged to evaluate the benefits and risks of each product before purchase*

**These questions and answers are taken from our email networks. Want to join the debate? Membership of the networks is free to both families and professionals supporting children or adults with severe learning disabilities. Application forms are available to download at [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) or email [network@thecbf.org.uk](mailto:network@thecbf.org.uk).**



# News

A round-up of what's been happening

## Channel 4 Dispatches Broadcast of 'Under Lock and Key'



In March this year, Channel 4 broadcast the highly significant Dispatches documentary 'Under Lock and Key'. Reviewing family allegations of poor care and abuse within a St Andrew's Healthcare hospital in Northamptonshire, the programme found evidence of widespread use of inappropriate seclusion, restraint and overmedication, culminating in at least one tragic death. Also featured was an

exploration of the rapid transformations possible with a person-centred, community-based care alternative. At a time when the Government has promised to close residential hospitals and invest in community support, the programme asks why commissioners still place young people in places like St. Andrew's.

## Anniversary of Winterbourne View

At the end of May this year we will mark the sixth year since appalling abuse at private hospital Winterbourne View was exposed by BBC Panorama. Winterbourne View is closed and the related staff have been brought to justice, but have lessons been learnt? In 2015, NHS England launched its Transforming Care agenda with the promise of closing residential inpatient units and providing care and support for people with a learning disability to live in the community. But one year on and we are still confronted with the reality of institutionalised care. We will be using the anniversary of Winterbourne to press for more rapid change in the lives of people with a learning disability.

## Department of Health to Publish Restrictive Interventions Guidance for Children

After a number of scandals, the Department of Health published guidance on the use of restrictive interventions for adults with a learning disability in 2014, but there is still no official guidance for its use in children. This has led to a worrying grey area for use of such methods in children's care settings and special schools. Two years ago, family carer Beth Morrison took a petition to the Scottish Government and managed successfully to introduce national guidelines for minimal use of restraint across Scotland. This year, the Department of Health is due to publish its own guidance extending the coverage to England and Wales. In the meantime, we have produced our own guidance which can be found here: <http://www.challengingbehaviour.org.uk/learning-disability-assets/statementonrestrictivephysicalinterventionswithchildren.pdf>

## Lenahan Review Published



After NHS England's Transforming Care programme set off in 2015, there was growing concern that the changes to care were neglecting to address children's services. The Department of Health commissioned Dame Christine Lenahan, CEO of the Council for Disabled Children to explore what changes needed to be made to make sure children and young people were getting the care they needed. The outcome was the Lenahan Review which the CBF has welcomed. Among other things, the review calls for different agencies to "stop passing the buck" and work together to develop local support from a young age. Read the full report

here: <https://www.gov.uk/government/publications/lenahan-review-into-care-of-children-with-learning-disabilities>

## CBF's Work on Medication

The CBF has carried out work for NHS England looking at views of family carers on medication and is due to publish a report outlining identified concerns which will be used to inform NHS work around over-medication. For many family carers medication was not being used as a last resort and there was not enough information provided about medication and alternatives. Following this, we are currently developing a pathway resource around medication for families. People interested in being involved are encouraged to contact us.

# Innovative, interesting or useful resources available free online.

## Working with People with Autism' Videos

If the person you care for has autism, these videos from the Social Care Institute for Excellence (SCIE) are an excellent introduction to what the diagnosis means, and the collaborative, person-centred approach to care.

Watch the videos at the following links: <https://goo.gl/linHxZ> and <https://goo.gl/yDB5nV>



## Mental Health Self-Care Starter Kit

Caring for somebody with a severe learning disability who may display challenging behaviour can be stressful and exhausting. It's sometimes hard to find time to look after your own wellbeing. This Self-Care Starter Kit from the The Blurt Foundation aims to help you take care of your mental health in the face of external stresses. <https://www.bluritout.org/self-care-starter-kit/>



## BILD Positive Behavioural Support Webinars

Behavioural Support (PBS). Recent topics have included the application of positive psychology to the PBS approach and how staff can better value their service-users. You can see the full list of recordings here: <http://www.bild.org.uk/capbs/capbswebinars/>

Found something interesting online you'd like to share? Email it to [communications@thecbf.org.uk](mailto:communications@thecbf.org.uk), post it to our Facebook page or tweet it to us @CBFdn.

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Created by Parents to Make the Difference

UK's largest parent-led residential care provider

### Autism, Epilepsy & Challenging Behaviours

Our approach is to tailor make environments and support packages for complex individuals coming through transition.

This approach has also led to a small number of individuals, previously in private hospitals, being successfully reintegrated into our social care environment.

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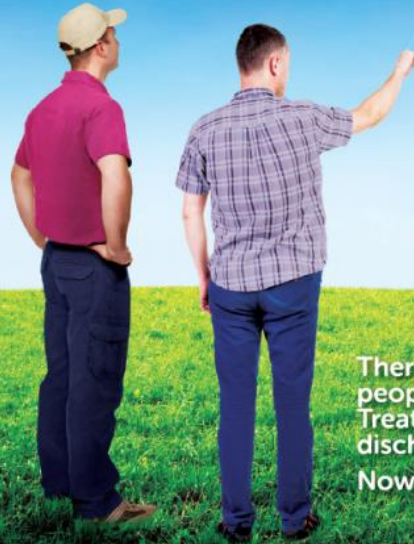
We provide a range of residential based specialist services for adults with learning disabilities and complex support needs.

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Our blog - [www.createdbyparents.com](http://www.createdbyparents.com)



There are over 2,000 people in Assessment & Treatment units awaiting discharge. Now there is one less...

This reconstruction is based on an actual event and outcome

Our range of services are designed to offer a 'real' choice to service users and their families, and are shaped to be flexible to meet the changing needs of people as they move from childhood to adulthood and beyond. We have locally based specialist education, transition, care and community support services for the most complex and vulnerable young people and adults.



### COMMUNITY SUPPORT SERVICES

High quality support and personal care to people of all ages when and where, and for as long as they need it.



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[senadgroup.com](http://senadgroup.com)

**SENAD**

## Want to advertise here?

E-Challenge is published three times a year and goes out to over 1000 families and professionals.

Please contact:

[communications@thecbf.org.uk](mailto:communications@thecbf.org.uk)

## What a Challenge!



*Peter Baker and his committed team*

This summer, CBF Supporter Peter Baker and his committed team, will be cycling from Lands' End to John O'Groats in aid of the CBF!

Last year Peter and two of his friends, Patrick Piper & Duncan Feathers, decided to cycle the length of the west coast of Italy from Pisa to Sicily - some 850 miles over 9 days. Their trip was supported with their luggage conveyed, so was not as hard as it seemed. On arrival in Catania they experienced a sense of anti-climax and knew they needed to get Lands' End – John O'Groats (unsupported – carrying their own stuff on the bike) out of their system. So here it is... Penzance – Tavistock – Cheddar – Ludlow – Preston – Gretna – Kilsyth – Ballaculish – Tain – John O'Groats, 917 miles, 55,330ft of climbing over 9 days 24th June – 3rd July.

They have generously agreed to take on this challenge with the goal of raising as much money for the CBF as they can. If you are able to help please visit their fundraising page - <http://uk.virginmoneygiving.com/PeterBaker19>

Thank you in advance of your support.

## Can you help us?

Did you know you can nominate us to receive a donation from your local supermarket or bank? Speak to a member of staff in your local branch or email Laura ([laura.brown@theCBF.org.uk](mailto:laura.brown@theCBF.org.uk)) for more information.

## Would you like to organise a fundraising event for the CBF?...

Drop Laura a line with a brief outline of your idea – whether you're thinking of holding a barbecue for family and friends or organising a charity ball or auction...we'd be happy to help with your planning!



## Happy Birthday CBF!

This February, the Challenging Behaviour Foundation marked its twentieth anniversary as a charity. From humble beginnings printing and distributing information out of a household garage, the CBF has grown over those twenty years to become a key organisation supporting thousands of families nationwide and influencing and campaigning for policy change nationally. Despite us not having achieved our ultimate goal – that of no longer having to exist – we have achieved a lot. But none of it could be possible without the contributions of our passionate staff over the years.

Diana Cutler a Trustee and volunteer is also celebrating twenty years with the charity having been one of the first people to give up her free time to assist CEO Viv Cooper in setting up the CBF. Meanwhile our Family Policy Lead, Gemma Grant, completes her tenth year, having first joined Viv as the organisation's Family Support Worker. We are also saying a sorry goodbye to our Admin Assistant and long-term volunteer Jo Read who first came to the CBF five years ago, as she moves to the coast and a new life by the sea.

All have contributed invaluable to the many support services and projects of the Challenging Behaviour Foundation over the years, and we would like to extend our warmest thanks to them.

## Thank You

I have known Peter for 20 years- we first met when I went to the Tizard Centre to talk to him, Jim Mansell and Glyn Murphy about my plans to set up a charity because of the lack of local support and services for my son, and the need for practical information for families. Over the next few years Peter was hugely supportive of my efforts to bring Daniel back (which meant working to get a service created for him) and patiently endured my regular rants about the unhelpful system and how long things take to change.

Peter has dedicated his career to improving the lives of children and adults with learning disabilities and their families, with his wealth of knowledge and experience. He is calm, thoughtful and wise – although equally frustrated by slow progress and the “swamp of inertia”. He is a valued and trusted friend, colleague and for the last 12 years a CBF Trustee. As he retires from this role, we thank him for his contribution and will miss him greatly – but we won't let him escape and we are delighted he will remain as a Trustee Advisor.

**Viv Cooper CEO of the Challenging Behaviour Foundation**

## 100 Club Winners

Recent winners of the CBF 100 Club, winning £25 each, were:

### January 2017:

Kym McMillan (Kent)

### February 2017:

Pamela Moseley (Dorset)

### March 2017:

Jan Seamer (Somerset)

All proceeds from the 100 Club help towards CBF running costs. Please get in touch if you would like to join for just £12

## Have your say

We welcome articles from parents and professionals. Please get in touch if there is something you would like us to write about.

## 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.

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# Resource order form

Please note that all of these resources can be downloaded free of charge on our website: [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

All our information and resources relate to the care of individuals with **severe learning disabilities** who are described as having challenging behaviour. We are happy to send resources **free of charge to parents/unpaid carers**.

	Cost	Number	Total £
<b>CHALLENGING BEHAVIOUR DVD RESOURCES</b>			
The DVDs provide practical support from professionals and family carers. Academics or learning disability professionals give expert guidance while family carers share their experiences. The DVDs introduce each topic clearly, explaining the key ideas and offering a wealth of practical information.			
<b>Everybody Matters: DVD</b> Getting the right person-centred support for adults	£31.50*		
<b>An Introduction to Challenging Behaviour: DVD</b>	£31.50*		
<b>Self-Injurious Behaviour: DVD</b>	£31.50*		
<b>Communication &amp; Challenging Behaviour: DVD</b>	£31.50*		
<b>Challenging Behaviour - Supporting Change: DVD</b> Learn about the causes of challenging behaviour and how to use a functional assessment to put appropriate positive behaviour support strategies in place. (Two disc set)	£63.00*		
*Free to parents/unpaid carers. Registered charities: DVDs £16.50 (or £33.00 for Challenging Behaviour - Supporting Change). Price includes postage & packing in the UK only. Outside UK p&ap £7.50 per item.			
<b>CHALLENGING BEHAVIOUR INFORMATION SHEETS</b>			
The information sheets are written by experts and provide practical support on a wide range of topics. Each information sheet contains a one-page summary, as well as a longer document providing more detailed information. The information sheets are suitable for both family carers and professionals.			
<b>Understanding Challenging Behaviour: Part 1</b>	£12.00*		
<b>Finding the Causes of Challenging Behaviour: Part 2</b>			
<b>Positive Behaviour Support Planning: Part 3</b>			
<b>Communication and Challenging Behaviour</b>			
<b>Health and Challenging Behaviour</b>			
<b>Impact of Caring on Families</b>			
<b>BASIC INFORMATION PACK (consisting of the 6 information sheets listed above)</b>			
The following additional information sheets are not contained in the basic information pack but may be downloaded from the Challenging Behaviour Foundation website or ordered separately:			
<b>Teaching New Skills</b>	£1.00*		
<b>The use of Medication</b>	£1.00*		
<b>The use of Physical Interventions</b>	£1.00*		
<b>Specialist Equipment and Safety Adaptations</b>	£1.00*		
<b>Planning for the Future</b>	£1.00*		
<b>Further Information for Family Carers</b>	£1.00*		
<b>Booklist for Professionals</b>	£1.00*		
<b>Difficult sexual behaviour amongst men and boys with learning disabilities</b>	£1.00*		
<b>Getting a Statement (Wales &amp; Northern Ireland)</b>	£1.00*		
SUB TOTAL CARRIED FORWARD			

\*All resources are free to parents/unpaid carers. Prices include postage and packing in the UK only.

/ Continued overleaf...

SUB TOTAL CARRIED FORWARD	Cost	Number	Total £
<b>For Families: Getting an EHC Plan (England)</b>	£1.00*		
<b>For Professionals: Developing an Education, Health and Care Plan (England)</b>	£1.00*		
<b>Getting Legal Authority to Make Decisions</b>	£1.00*		
<b>Pica (eating inedible objects)</b>	£1.00*		
<b>Mental Health Problems in People with Learning Disabilities</b>	£1.00*		
<b>Ten Top Tips</b>	£1.00*		
<b>Self-Injurious Behaviour</b>	£1.00*		
<b>IN-DEPTH RESOURCES</b>			
<b>Paving the Way</b> A guide for commissioners on how to develop effective local services for children with learning disabilities whose behaviours challenge			
<b>8 Ways to Get a House</b> A guide to help families think about the different types of accommodation and how they are funded.			
<b>A Guide for advocates (England and Wales)</b> A comprehensive, practical guide for professional advocates; or family carers advocating for their family member.			
<b>PSB Study Pack for Schools and Colleges</b> The Positive Behaviour Support study pack is designed for teachers to increase understanding of behaviour. Note: This resource is only available for schools and colleges.			
<b>Planning for the Future: Information Pack</b> England / N Ireland / Wales			
For anyone planning for the future of children aged 12 and upwards (transition), or concerned about the support needs of adult family members.			
Read more about all our in-depth resources online at <a href="http://www.challengingbehaviour.org.uk">www.challengingbehaviour.org.uk</a>			
<b>DONATION – please consider a donation to support our work. All proceeds go towards helping families caring for individuals with severe learning disabilities whose behaviour challenges. Thank you.</b>			
*All resources are free to parents/unpaid carers. Price include Postage & packaging in the UK only. Outside UK p&p £7.50 per item.		<b>TOTAL</b>	

Please consider making a donation to help us support more families. If you would like to donate regularly, please tick here  to receive a standing order form.

Gift Aid means we can claim back the tax on your gift (25p for every £1 you give) at no extra cost to you. Please tick here  to confirm that you would like CBF to claim tax paid on this gift and any eligible past or future gifts.

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Your personal data may be held on computer and will be kept in accordance with the Data Protection Act 1998 under which we are registered as a data controller. This data will not be passed on to any third party without prior consent.

Please make **cheques payable** to the Challenging Behaviour Foundation and return to the Challenging Behaviour Foundation, The Old Courthouse, New Road Avenue, Chatham, Kent, ME4 6BE

Alternatively, go to [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) to order online

# The CBF – how you can help

*Did you know.....?*

- **We are a registered charity and rely on donations, grants and fundraising to finance our work.**
- **We do not charge family carers for services or resources.**
- **To keep costs down much of our work is carried out by volunteers.**
- **Regular giving by standing order makes your money go further by keeping down administrative costs.**
- **You can 'Gift Aid' your donation if you are a UK tax payer, this allows us to receive 25% extra on top of your donation without any further costs to you.**
- **You can fundraise for free! There are a number of ways to donate and raise money for us without spending any extra money. See our website for details.**

Your support really does make a big difference to us. So, thank you!

For more information please email [fundraising@theCBF.org.uk](mailto:fundraising@theCBF.org.uk)

## The Challenging Behaviour Foundation

Registered charity number 1060714 (England and Wales)

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