# Challenge

SCLD

The Challenging
Behaviour Foundation

Winter-Spring 2021

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# Consistency in uncertain times

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

# **CBF and SCLD have teamed up for this edition!**

The Scottish Commission for People with Learning Disabilities' (SCLD) vision is of a fairer Scotland where people with learning/intellectual disabilities live full, safe, loving and equal lives. For these reasons, we are delighted to work with the Challenging Behaviour Foundation (CBF) on this joint newsletter that brings together a range of information that is aimed at family carers who are supporting children or adults with severe learning disabilities who display behaviour that challenges. During the pandemic, we have engaged with families who have described how challenging the extended bouts of isolation have been. We hope the information and practical guidance in this newsletter provides some measure of support in these incredibly difficult times.

Linda Mitchell
Head of Delivery
at SCLD

The CBF and SCLD share common aims, including working together and with families to ensure that they get practical information and support that they find helpful. We know that over the last 12 months there have been numerous unforeseen and additional uncertainties for families caring for children and adults with learning disabilities whose behaviour challenges. We are really pleased to partner with our friends at SCLD for this newsletter to ensure that we both reach more families. Feeling isolated and alone is something that families who get in touch with us often describe - and the pandemic has heightened those feelings. In this newsletter 2 family carers share experiences that many of you will identify with.

CBF and SCLD are both committed to finding ways to connect people and provide a range of ways to deliver support and practical information. This newsletter is themed around managing uncertain times and it contains lots of information we hope you find useful. Do get in touch if you would like any of the resources featured in this newsletter or to access support from either organisation.

Vivien Cooper Family carer and CEO of the CBF

Contents	
Consistency from the Family Carers' Email Network	2
PBS Community of Practice Scotland Update from CBF's Family Support Service	3
Pica: Kate and Laura's story Development of Pica workshops	4-5
Restrictive practices and SNRRP	6
Family story about lockdown Making It Happen - resource	7-8
COVID-19 Guided Self-help resources Carers' Catch Ups	9
Family carer well-being and resilience	10
Vaccination Update MELD project	11
Thank you and more information	12

Who is SCLD? The Scottish Commission for People with Learning Disabilities is an intermediary organisation for the learning disability sector in Scotland. We work closely with the Scottish Government as a delivery partner in the implementation of The keys to life, Scotland's learning disability strategy. Our vision is of a fairer Scotland where people with learning/intellectual disabilities live full, safe, loving and equal lives.

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

# **Consistency from the Family Carers' Email Network**



During the pandemic, many things were disrupted but sharing experiences, issues and solutions with others who understand continued and was a source of information and support for many.

The wordcloud above is a visual representation of the text from a recent email exchange from the CBF's Family Carers' Email Network. One family carer asked if anyone had managed to visit their child in a residential care setting, as the family in question had been unable to visit their 27-year-old daughter since before the November lockdown. The numerous responses from fellow network members were informative and supportive. The person who had asked the initial question responded: "Thank you so much for all your replies; it's so depressing, but at the same time comforting (if that's the right word!) to know that there are other families going through similarly awful experiences."

In lockdown, and afterwards, we need consistency - both for relatives with learning disabilities and the approaches carers take to their support. Providing consistent support to a loved one is the kind of topic that family carers discuss on the Family Carers' Email Network. This Network is especially for family carers of children, young people and adults with severe learning disabilities whose behaviour challenges. It enables you to be in touch with other families around the UK; you can share experiences, information and receive support - without any obligation to reply or to identify yourself. One parent said "It is good to get information, advice and encouragement from other families who have faced similar problems to ours. It is also good to be able to help others from our own experiences."

- You can join the Family Carers' Email Network by emailing: network@thecbf.org.uk
- Look through this newsletter to find other sources of information and support, including the Positive Behaviour Support Community of Practice, the Scottish Network for Reduction of Restrictive Practices, Carers' Catch Ups and the Family Support Service.
- Watch out for the CBF's brand new website, to be launched this Spring, with easy-to-find information and guidance: www.challengingbehaviour.org.uk

#### **Positive Behaviour Support Community of Practice Scotland**

Following the publication of the <u>Coming</u>
<u>Home</u> report in 2018, the Scottish Government
made a commitment to develop a Positive
Behaviour Support (PBS) Community of Practice
(COP) for Scotland.

The Scottish Commission for People with Learning Disabilities (SCLD) with support from BILD <a href="https://www.bild.org.uk/uk-pbs-alliance/">https://www.bild.org.uk/uk-pbs-alliance/</a> have established a PBS Community of Practice for Scotland: <a href="https://www.scld.org.uk/positive-behaviour-support-pbs/">www.scld.org.uk/positive-behaviour-support-pbs/</a>



#### The PBS COP Scotland is focussed on:

- Leading the dialogue and discussion about PBS in Scotland
- Supporting the implementation of PBS in Scotland
- Delivering national events and webinars on PBS
- Sharing good practice and learning about PBS
- Ensuring that all sectors providing services to people with learning disabilities are well represented and involved with the work of the CoP.

The PBS COP Scotland is open to anyone in Scotland with an interest in PBS:

#### http://eepurl.com/g9-F8n

To find information about other collaborative communities see: <a href="https://www.bild.org.uk/uk-pbs-alliance/">www.bild.org.uk/uk-pbs-alliance/</a>

BILD also has a range of helpful resources:

www.bild.org.uk/resources/

For more information about PBS look at the CBF's website: <a href="https://www.challengingbehaviour.org.uk/">https://www.challengingbehaviour.org.uk/</a> information/information-sheets-and-dvds/positive-behaviour-support.html

If you do not have internet access and would like a copy of any of the resources mentioned, or more information, please contact SCLD using the contact details on the last page of this newsletter, or the CBF using email <a href="mailto:info@thecbf.org.uk">info@thecbf.org.uk</a> or telephone (general enquiries) 01634 838739.

## **Update from the CBF's Family Support Service**

We are happy to announce that the CBF Family Support Team has a new member!

Elissia is our new Family Support Triage Officer - she will now answer the phone when you call us. Don't worry, you can still talk to Charlie, Holly or Gemma if you need to; Elissia will put you through or book you an appointment.

Elissia can also book you an appointment with our new peer-to-peer telephone listening ear service. This is still in development but please give us a call on 0300 666 0126 to find out more, especially if you don't have internet access.

Emma's Carer's Catch Up takes place on Zoom every other Monday at 11:30. Email: carerscatchup6@thecbf.org.uk for more information.

Don't forget we have ongoing funding to provide support to families going through a transition or where a loved one is in an assessment and treatment unit (ATU). If this is you, please get in touch; we want to help!

Get in touch with the Family Support Service: <a href="mailto:support@thecbf.org.uk">support@thecbf.org.uk</a> or 0300 666 0126.







# Pica: Kate and Laura's story

Laura my lovely young daughter is now 28 and has a severe learning disability, complex communication disorder, and ongoing needs.

She has a rare syndrome, Wiedemann Steiner Syndrome, which is a multi-system syndrome so affects Laura in many ways. Laura lives at home with her mum and attends a day centre 5 days a week. She is a happy sociable young lady with a great sense of humour but can also be very mischievous when the mood takes her.

Laura can and will display behaviours described as challenging when her needs are not being understood or met. She will also exhibit selfinjurious behaviours when frustrated or in pain. We have an excellent Communication Passport that gives Laura a voice and shows her for the unique individual that she is - it is also a great support and teaching tool for all the staff that support Laura, and can be downloaded and read at:

#### www.mycommpass.com

My greatest concern for Laura is her Pica behaviour - it feels like we are walking on a tightrope at times. Laura will eat mostly materials; cushions, clothing, and bed clothes. I have to admit she has always loved chewing things and putting things in her mouth and I put that down to her need for sensory feed-back. We supply Laura with a chewy necklace that is attached to a weighted doll, but she will bite into most materials, like the cover of her i-pad if no one is watching her, so she is supervised at all times.



#### What is Pica?

Pica refers to eating objects which are not suitable to be eaten, such as stones, faeces and clothing.

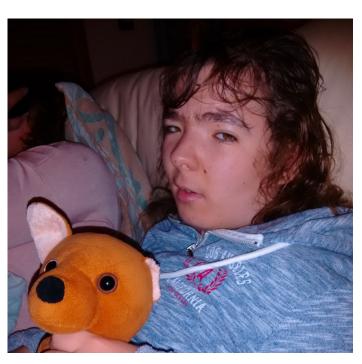
#### What is Polydipsia?

Polydipsia involves the constant desire to drink any type of liquid (for example, bleach or toiletries) even if the individual is not thirsty.

#### More information

The CBF has an information sheet: <a href="https://www.challengingbehaviour.org.uk/">www.challengingbehaviour.org.uk/</a>
<a href="https://www.challengingbehaviour.org.uk/">understanding-behaviour/pica-polydipsia-sheet.html</a> or phone 01634 838739 to request a paper copy.

I guess the most dangerous time for Laura is during the night as she eats her bed clothes. We have cameras everywhere and we have bought special bed wear from prisons which are supposed to be pretty tough against tearing, but she has bitten through them. We spent over £1000 on special bed linen and durable materials, but nothing has survived.



Fido's ear is missing - somebody looks guilty!

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# Pica: Kate and Laura's story - continued

To date Laura has had two life saving surgical procedures to remove materials from her stomach. It is a very stressful situation for Laura and her family as we constantly worry about this behaviour, especially as there is little known or literature on why it happens and what we can do to reduce it - all I can do is highlight the trauma it causes.

What I have found is that many medical staff know nothing or very little about Pica and the danger and the trauma it can cause to the individuals life! When Laura has been admitted, if I didn't insist on the likelihood of Laura becoming obstructed and hadn't insisted on how serious her condition was, she might not be here today. I think every hospital should have a check list on the dangers of Pica and the questions to ask, but most importantly if a parent or carers says they are worried please listen, they know their child or the person they are supporting, they will recognise the smallest change in the individual with Pica and this is an indication something is not right, waiting and not taking action could be fatal for that person.

Just prior to Christmas my daughter managed to get into the padding in her nappy (she had never

done this before) I have a camera in her bedroom and heard her retching, I managed to dislodge the piece of padding from her mouth. We now have her in new zip up the back sleep suits that cost £200 for four but at least she is safe from eating her nappy. I am constantly worried about what she will do next but she has a one to one so hopefully we can continue to keep this wonderful unique little lady of mine safe, she has a great happy life but Pica will always be a concern.

#### Kate - Laura's mum



Laura and her sister

# **Development of Pica workshops**

The CBF's Pica Awareness workshop has been co-designed for professionals/ support staff supporting children, young people or adults who have severe learning disabilities and display Pica behaviour (eating inedible objects) and/or polydipsia (drinking fluids).

In our work with families support staff and professionals it has become clear that there is a lack of understanding of what pica is and the risks associated with it. This results in a lack of awareness about how to support someone with pica therefore further increasing risks and failing to address some of the reasons why this type of behaviour can occur.

The Pica Awareness workshop is delivered to support staff who will benefit from understanding the risks to the individual, the importance of understanding the behaviour characteristics and the need for vigilance. The workshop aims to ensure that support staff have a good, practical, introduction and understanding of Pica behaviour and how to support people to keep them safe.

#### **Further information about workshops**

Please contact the CBF for further details about our workshops by: emailing <a href="mailto:workshops@thecbf.org.uk">workshops@thecbf.org.uk</a> or calling us on 01634 838739.

# **Frequently Asked Question**

Unfortunately, children and adults who display behaviour that challenges are often subjected to restrictive practices. Individuals and organisations are working together to highlight the issues, to promote positive alternatives and ensure that if restrictive practices are used they are recorded and reported.



## What do we mean when we talk about restrictive practices?

The terms restrictive practices can describe many different acts and includes: physical restraint; seclusion, chemical restraint, environmental restraint and mechanical restraint:

**physical restraint** or intervention refers to the use of direct physical force to restrict someone's freedom of movement

**seclusion** is where a person's freedom is restricted by forcibly confining them to a specific space, e.g. a bedroom, or seclusion room

**chemical restraint** – refers to the use of medication to manage a person's behaviour

**environmental restraint** – refers to the use of physical barriers to restrict someone's freedom of movement, such as locked doors, either to restrict someone in an area e.g. their bedroom, or to prevent them accessing an area, e.g. the kitchen

**mechanical restraint** – refers to the use of equipment, which restricts freedom of movement, for example some types of harness, and restraint chairs

Other restrictive practices include social coercion, blanket rules, restricting access to items e.g walking aids, and restraint by default e.g. an individual's movement being limited by deliberately not being assisted or their power chair switched off.

# Scottish Network for Reduction of Restrictive Practices (SNRRP).

The SNRRP is facilitated by SCLD and brings together a wide range of stakeholders, including professionals, family carers and individuals with lived experience, who have expertise and a shared commitment to working towards the reduction of restrictive practices.

Key area of focus for the SNRRP are:

- Eliminating the misuse of restrictive practices
- Facilitating cultural change to promote human rights
- Supporting more positive approaches to working with people
- Sharing best practice and learning
- Supporting the development guidance
- Supporting workforce development
- Promoting best practice in monitoring and reporting

The SNRRP has strong connections with the UK Restraint Reduction Network (RRN) and the CBF's Reducing Restrictive Interventions - Safeguarding Children and Young People (RRISC)\* group.

These networks are creating and providing opportunities for increased partnership and sharing of best practice at a Scottish, UK and international human rights level.

#### More information:

www.scld.org.uk/the-scottish-network-for-reduction-of-restrictive-practices-snrpp/ www.restraintreductionnetwork.org/ www.challengingbehaviour.org.uk/driving-change/restraintandseclusion.html

\*RRISC is a collaborative of individuals and organisations working together to tackle the issue of restrictive interventions against children and young people across the UK. For more information see CBF's webpage <a href="https://www.challengingbehaviour.org.uk/driving-change/restraintandseclusion.html">www.challengingbehaviour.org.uk/driving-change/restraintandseclusion.html</a> or call us on 01634 838739.



# Will things change after lockdown? A family's perspective

Families of people with severe learning disabilities have had very varied experiences of lockdown this past year. Many have struggled with the extreme situations of either caring for their family member at home full-time with little or no support, or being unable to spend time with their relative at all, as they shielded in their care home or shared home. Here, Cathy and Mark share their individual experience of lockdown, in which they fully isolated as a family bubble - a way of living that was not entirely new to them

We are the Parents of a wonderful 14-year-old boy, Malachy, who has Autism, Severe Learning Disabilities with behaviours that challenge. He has three younger siblings. Malachy has been an inpatient at an Assessment and Treatment Unit since September 2019, when he was admitted and detained at 12 years of age. Malachy remains an inpatient due to ongoing negotiations with the local community trust team regarding the provision of appropriate support, to enable Malachy to return home to his family with the right environment and support staff.

When the initial lockdown was introduced in March 2020 our immediate realisation was that due to our caring responsibilities with Malachy and his additional needs, we as a family unit had already been effectively 'living a life in lock-down' for years. The activities and places that Malachy could be taken to for leisure and fun activities for a child of his age, such as play parks and swimming centres, have been 'no-go areas' for us long before any sort of lockdown.

Throughout the various lockdown periods, the centre in which Malachy is a patient has acted with great flexibility and with Malachy's best interests at heart. We were given a choice at the beginning of lockdown. We could either say good-bye to Malachy as he would have to isolate in the unit, or we as a family could 'bubble' with him and therefore selfisolate at home which would allow our daily contact with our son. We were only permitted to leave home to collect Malachy and bring him home for few hours. It was a no brainer! Neither Malachy, nor us, would not have coped with not having contact with each other. We are very lucky to have such compassionate doctors and a team who recognised and weighed up the risks to Malachy of Covid-19 infection but also the serious risk to his mental health and overall well-being.

For the first few months of lockdown Malachy was in his element as he was returning home on a daily basis. However, as lockdown has progressed, returning home was no longer enough to satisfy Malachy's needs; he wished for more and the number of incidents of challenging behaviours increased. In this respect we are working with Malachy's centre to create a better balance



between time at home and time in the centre. The fact that in this third lockdown special schools have remained open has also been a bonus as Malachy has been able to attend school even when other schools have been closed.

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#### Will things change after lockdown? Continued.....

Coming out of lockdown we still believe that for us, and families in similar situations, society can be inaccessible. There remains a variety of inequalities for those with learning disabilities and challenging behaviours, and we are not hopeful that this period of lockdown will solve these long-standing issues. In all likelihood we will return to a world where we feel we live in a semi-lockdown existence to meet Malachy's specific needs. We appreciate that many other families linked to the CBF will be in similar situations and would encourage everyone to stay strong and focused on those special people in our lives, knowing that through the CBF there is great support, knowledge and experience to help us through any difficult times. **Cathy and Mark.** 

#### **Family Support Service**

The CBF's family support helpline is available for families with children or adults with a severe learning disability. Get in touch by email: <a href="mailto:support@thecbf.org.uk">support@thecbf.org.uk</a> or 0300 666 0126.



# Making It Happen: Positively managing risk for children and adults with severe learning disabilities

Throughout the pandemic we have all been managing risks – and putting things in place to minimise those risks to help us keep safe. Risk management should be a careful process to enable you to do things safely, rather than to prevent activities happening. The CBF has put together a resource to help balance taking measures to keep people safe from the virus and the risks to health, wellbeing and quality of life when normal activities and face to face visits with family are suspended.

#### **Key principles**

- People should not be prevented from taking part in activities, attending school or services simply because they have complex support needs or display challenging behaviour.
- Risk management is a process to identify potential risks.
- Positive risk taking involves identifying how risks can be eliminated, minimised, mitigated and managed to *enable* the person to take part safely wherever possible.
- The focus should be to choose the least restrictive option that successfully mitigates risks and keeps the person and others safe.

#### Steps to follow to positively manage risk:

- Specify the activity that needs to be assessed and risks that need to be managed
- Clarify the risks of engaging in the activity as currently planned. It is useful to estimate the likelihood and the potential impact of these risks
- Clarify the risks of not engaging in the activity. It is easy to forget this as the risks may be less concrete and more long-term
- Identify how each specific risk can be mitigated or managed. Often there is more than one way of mitigating risk and different options might be weighed in terms of restrictiveness and/or preference
- Throughout the process key stakeholders should be involved including, as much as possible, the

- person with a severe learning disability and family members and others involved in their support. The aim should be to reach an agreement about the way forward.
- At the conclusion of the process a decision needs to be made. In most cases this will mean an activity continues or begins and follows identified procedures to mitigate risk. However due to lockdown some activities will be cancelled. If this is the case, alternative activities that meet as many as possible of the original activity's goals should be considered.
- The decision should be regularly reviewed as the risk of covid-19 changes

The full resource includes information about what to do if you disagree with how risk is managed.

#### Where can I get the resource?

The full resource is available on the CBF website: COVID-19 - Information and resources
For a printed copy call 01634 838739.

Information sheets about the legal principles underpinning positive risk taking during Covid-19 are also available on the CBF website, or by calling us.

Thank you to Doughty Street for their contribution to these summaries.



# Useful resources from SCLD to help during the pandemic

Since the beginning of the pandemic and first UK-wide lockdown in March 2020, SCLD has been working with Scottish Government and other partners to produce guidance for people with learning disabilities on the Coronavirus outbreak and how people can best protect themselves.

The resources include a range of information: from Easy Read guidance, activities, mental health information, guidance for supporters and practitioners, plus videos and planners. You can view these resources via our Google Drive resource bank accessed through the SCLD website homepage: <a href="https://www.scld.org.uk">www.scld.org.uk</a>

#### **COVID-19 Guided Self-help resources**

The University of Glasgow, with assistance from colleagues at Lancaster University, the University of Oxford and the University of Warwick, developed a series of guided self-help booklets, designed to support people with mild to moderate learning/intellectual disabilities during the COVID-19 outbreak.

The booklets can be used with the support of family members, friends, volunteers and carers and are also suitable for social work and health professionals.

Although the booklets are intended to give people with learning/intellectual disabilities an opportunity to talk through their feelings with people providing support to them, recent feedback has shown them to be useful for individuals with a range of needs, including by family carers themselves. There is a guide accompanying each booklet, explaining how the content can be delivered.

This self-help booklet series is intended to help you to work in partnership with people who have learning/intellectual disabilities, to talk about their feelings and make plans for staying well at this difficult time. The titles cover topics such as: feeling down, feeling anxious, getting a good night's sleep, keeping physically active and dealing with problems, plus there are some guided relaxation videos.

The booklets and guides were updated in December 2020 to reflect the difficulties caused by the changing rules which many have found confusing and the challenges presented by dealing with the pandemic during the winter months.

#### Where can I get them?

The booklets are free to download, however printed copies of the resources are available to those living in Scotland only.

#### To order printed copies (Scotland only):

Download or request an order form and email it to admin@scld.co.uk

Phone SCLD on **0141 248 3733** to place your order.

You can find out more about the booklets and download them on the SCLD website by visiting this link: <a href="https://www.scld.org.uk/update-to-the-covid-19-quided-self-help-booklets/">https://www.scld.org.uk/update-to-the-covid-19-quided-self-help-booklets/</a>



CBF's Carers' Catch Ups

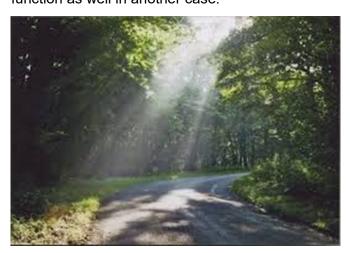


Carers' Catch Ups are friendly and informal Zoom calls for families to share successes and support one another. If you have a relative with a severe learning disability and want to chat with people that understand the challenges you may be facing, email: network@thecbf.org.uk to register your place now!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

# Family carer well-being and resilience

For many family members their role as carer is not just around providing support for their loved one. Family carers often become informal care managers who coordinate care and support across multiple settings and providers. As the demands of this role increase so does the risk of stress, burnout, decline in own health and the ability to fulfil other roles.

The term resilience has often been used to describe people's behaviour in response to a situation, for example: "Jake is coping well, he is very resilient." However, 'resilient' is not something you are, or not, rather resilience is a much more of a dynamic ever-evolving process. Resilience is highly situation-related, meaning that a person who seems to cope in one situation may not function as well in another case.



#### Why is resilience important?

You are the heartbeat of your family and can only look after others who depend on you if you look after yourself. You spend so much time looking after other people that you may forget yourself - but you are important too and deserve to be cared for as much as anyone else.

Looking after yourself is not being selfish; being aware of your own feelings and needs means that you will have greater resilience to carry on – the better you feel, the better you can help others to feel.



#### Positive pathway to resilience

Remember resilience is a process.

Here are some steps which may be helpful.

#### Keep a focus on:

- Sense of purpose (having goals and something to aim for makes you better equipped to deal with difficult times)
- Positive mental attitude (having a positive but realistic approach to what you can achieve/ manage)
- Connection with others (asking for help, sharing, and talking)
- Determination (being proactive and not giving up)
- Taking control (recognising what we can do something about and what that action might be)
- Looking after yourself (having a healthy lifestyle, taking time to relax)

Adapted from Cranfield Trust's webinar: Managing Resilience in Difficult Times: www.cranfieldtrust.org

#### You do not have to struggle alone

Do not be afraid to ask for help; many family carers will be feeling the same way as you and asking for help, and looking after your own needs is a strength, not a weakness. Reaching out and taking the help that is there for you is the best way to look after the people who matter to you. Notice who is reliably there for you to listen and offer practical support

Soldiering on alone can lead to longer term stress, which, if ignored, can result in burnout.

#### Resources

The CBF is offering free online support for family carers via video call during the COVID-19 pandemic, including Carers' Catch Ups and Behaviour Chats. Consult our website for more information:



#### www.challengingbehaviour.org.uk

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.

# **Vaccination update** (up-to-date as of end Feb 2021)

As of the 15th of February, individuals in the top four vaccine groups should have been offered their first dose of the COVID-19 vaccine – these groups include all clinically extremely vulnerable individuals, individuals aged over 70, older adults in residential care homes, their care home workers, and all frontline health and social care workers. This means that vaccines will now be offered to priority groups five (all those aged over 65) and six (all those aged 16-64 with certain *underlying health conditions*), across all four nations of the UK.

This week, the joint committee on vaccination (JCVI) announced that all individuals with learning disabilities will be vaccinated as part of priority group six, whereas previously only individuals with 'severe and profound learning disabilities' were to be considered a priority for vaccination in the UK-wide JCVI priority list. This welcome news means that vaccination priority will reflect the increased risk to COVID-19 that individuals with learning disabilities have, and it will also be extended to people with mental illnesses which cause functional impairment.



COVID-19 VACCINE

Accessibility and reasonable adjustments for individuals with severe learning disabilities whose behaviour challenges



Group six also includes *unpaid carers*, meaning that if you are in receipt of a Carer's Allowance, or are the main carer for an elderly or disabled person whose welfare may be at risk if you fall ill, then you too should be offered the vaccine in group six. Please speak to your GP about getting the vaccine if you or your relative are in either of these groups.

There are 1.2 million people in England with a learning disability – but only around 250,000 of these people are thought to be on the GP learning disability register, which is the means through which individuals will be identified as requiring a vaccine. It is important that you contact your GP surgery to ensure that your relative is on this register, which will also entitle them to annual health checks and future vaccinations.

For info on accessing the COVID-19 Vaccine – including requesting reasonable adjustments – see the CBF's COVID-19 Vaccine – Accessibility and Reasonable Adjustments information sheet. Contact us (info@thecbf.org.uk or telephone 01634 838739) if you would like to order a copy to be posted to you.

Are you a family carer of a child with a learning disability whose behaviour challenges? Do you have any experience of child learning disability services?

Are you interested in joining a Family Carer Advisory Group?



This is an exciting new research project, led by the University of Warwick, mapping child learning disabilities services in England. The project is looking for family carers to join a family carer advisory group.

Family carers should have experience of community-based services for children with a learning disability and behaviours that challenge (e.g., a specialist "challenging behaviour" team, child learning disability team or CAMHS Learning Disability service).

You will receive a £50 voucher for each meeting you attend. The advisory group will start meeting virtually with the possibility of future face to face meetings to be reviewed depending on circumstances. Meetings will take place over the next four years.

If you would like to get involved please Email Siobhan. Humphreys@thecbf.org.uk or call 01634 838739.

We actively encourage applications from diverse backgrounds, including Black, Asian and Minority Ethnic (BAME) family carers, as well as family carers from Scotland, Northern Ireland and Wales.

#### **London Landmarks Half Marathon**

Keith Ridge, the Chief Pharmaceutical Officer for England, is running the London Landmarks Half Marathon later this year to highlight the CBF's work and to raise money for us to continue that work. It will be his first-ever half marathon run!

Please support Keith: <a href="https://uk.virginmoneygiving.com/KeithRidge1">https://uk.virginmoneygiving.com/KeithRidge1</a> If you want to help Keith, but cannot contribute on-line, call us on 01634 838739. Thanks to Keith and his supporters.



# **Donating to the CBF**

A big thank you to all those who support us with regular and one off donations through Virgin Money Giving, Donr and direct debits through our bank.

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

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: <a href="https://www.challengingbehaviour.org.uk/support-us/donate.html">www.challengingbehaviour.org.uk/support-us/donate.html</a>

Why not purchase a number, or two, as a Mother's Day or Easter gift for friends and family? To sign up please email: <a href="mailto:info@thecbf.org.uk">info@thecbf.org.uk</a> or call us: 01634 838739.

# More about SCLD....

SCLD works for people with learning/ intellectual disabilities, aiming to create an environment in Scotland in which systems and culture are changed to ensure people with learning/intellectual disabilities are empowered to live the life they want in line with existing human rights conventions.



To get in touch with SCLD:

Visit our website: www.scld.org.uk - Phone us on 0141 248 3733 - Follow us on Twitter: @SCLDNews - Find us on

Facebook: @ScotCommission

# Support and funding at the CBF

During this 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 are still being held, (see page 9) and we continue to connect by email to people in similar situations, providing some additional comfort, advice and support.

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: <a href="https://www.challengingbehaviour.org.uk/support-us/support-us.html">www.challengingbehaviour.org.uk/support-us/support-us.html</a>

If you would like to help us in continuing to support families during this time please consider donating: **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.

Thank you to The Scottish Commission for People with Learning Disabilities' (SCLD), who kindly supported us to send out printed copies of our newsletter to family carers this month. It is important that we provide a range of accessible information and support in different formats for families during this difficult time. If you know somebody who wants to be added to the mailing list for future newsletters 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.