

Challenge

Summer 2008

Challenging
BEHAVIOUR
foundation



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

The newsletter of The Challenging Behaviour Foundation

Finding the cure?

When my one year old son started banging his head we were told that one possible solution would be to sedate him.

The social model of disability is now generally accepted and reflected in all current Government policy, but there are still some remnants of the medical model which give cause for concern.



Vivien Cooper

The social model of disability holds that it is society that disables individuals: we ("society") are not inclusive and we create barriers for some people. For example, the entrance to a building may be via steps, and therefore not accessible to a person who uses a wheelchair, or information may be inaccessible: simple adjustments can overcome these issues.

This social model of disability replaced the medical model, which viewed people with disabilities as having impairments that needed "fixing": a medical intervention was required to "solve" a problem. Hence the long-stay hospitals for people with learning disabilities.

Bringing up a child whose behaviour is very challenging is immensely difficult. But every individual is different. There has been amazing progress in the field of medicine, but there is no wonder drug that provides a blanket "cure" for challenging behaviour because the causes and reasons for the behaviour are varied.

At the CBF we have heard from some families who have found that a particular medication has been

beneficial, which is great. But equally we hear from many more who are offered medication as the only option, or families whose sons and daughters are on a whole cocktail of medicines, built up over time to attempt to combat side effects. Surely this is the medical model in its

purest form!

In this issue of 'Challenge' we focus on the use of antipsychotic medication (ie. medication for mental health issues) used in the treatment of challenging behaviour in individuals with learning disabilities. We look at some of the research (both new and not so new), some of the guidance relating to the use of medication, and hear from both professionals and families.

there is no wonder drug that provides a blanket "cure" for challenging behaviour

As a mum, I want to know that the proposed solution is thought through: what caused the problem, what are the available options, is it likely to work, will it have positive outcomes and how we will check. Families need information and support in order to be confident about what is and what is not acceptable.

• **Vivien Cooper**

Chair of Trustees and Founder of the Challenging Behaviour Foundation

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Pica refers to eating objects which are inedible such as stones, faeces, clothing and cigarette butts

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

Medication's what you need?

Medication designed for psychiatric illnesses have found their insidious way into the lives of many people with learning disabilities

When I was growing up, the Guinness Book of World Records had Roy Castle on the TV showing kids what four hundred tap dancers looked like. They looked frozen stiff. The theme song of *the show told me "Dedication! If you want to be the best/If you want to beat the rest/Whoa, dedication's what you need..."*

When I began working in services for people with learning disabilities and a challenging reputation, being of a satirical bent (my mother said I'd smart myself into an early grave), I would at times hum quietly under my breath a similar refrain, changing the words to "*Medication! Medication! Medication's what you need...*" as clients stumbled about.

Because people living there 'challenged' they had lots of psychotropic medication (drugs that act on the brain). They still challenged, mind. But one drug stopped the side effects of *that* drug, which countered

this other drug... you get the idea.

There is no pill to stop a specific behaviour. Even so, medication designed for psychiatric illnesses have found their insidious way into the lives of many people with learning disabilities, and more worryingly, into the thinking of services and professionals.

medication was primarily being used for general tranquillisation

Challenging behaviour does not of itself indicate a pathological psychiatric disorder, and yet in one study (Molyneux, Emerson & Caine, 1999) 66% of people with severe learning disabilities had been prescribed anti-psychotic medication despite the absence of any first-rank symptoms. Medication was primarily being used for general tranquillisation.

Sadly drug treatments provide the

mainstay of management of challenging behaviour in learning disability provision. And people tend to stay on these compounds for a long, long time. But medication (imagine little white pills with the word BEHAVE scored in them) is not as effective in the long term as understanding why someone behaves as they do, it's not as helpful as teaching replacement skills. Popping a pill is not an answer of itself. Take medication and there are side effects. One of the side effects of teaching skills is that the person may actually end up with a life.

A couple of years ago I supported a wonderful woman with learning disabilities on an acute psychiatric ward (boy, did this ever open both our eyes). We noticed a lot of medication. People rattled. We also noticed the pens provided by drug reps. We noticed the free pizzas, the small innocuous gifts, the contributions to social events for staff. Patients got something too. Little branded pills.

medication is not as effective in the long term as understanding why someone behaves as they do

Popping a pill is easy. It may be a pragmatic option when nothing else is available, but an answer for challenging behaviour it certainly isn't.

Medication may help some people, but it's not compulsory, and the evidence is not as overwhelming as its use suggests. Medication is not a panacea. It's often a placebo. Different thing altogether. So I'd go for Roy Castle's advice any day: "*Dedication's what you need.*"

• Tony Osgood

Lecturer in Intellectual & Developmental Disability, Tizard Centre University of Kent



THINKING ABOUT MEDICATION

Did you know?

- New research shows a greater reduction in challenging behaviour through taking a placebo (sugar pill) than taking antipsychotic medication! (Read more on page 4)
- "*Third parties may seek out low-effort solutions, such as a pill and an occasional medical appointment. They are less likely to undertake extensive analysis of the environment, including their own inappropriate practices, that might be contributing to the problem*" (Sturme, 1999).
- The recently published guidance from the Royal College of Psychiatrists (*Challenging Behaviour: a unified approach*) states that medication for people who present challenging behaviour should only be started following a thorough process of assessment, diagnosis and formulation that has confirmed that a psychiatric disorder is present or that significant psychiatric symptoms exist.
- Every drug has licensed uses, for example Risperidone is licensed for acute and chronic psychoses and mania. It is not licensed for challenging behaviour. To find a details of the licensed uses and dosages of drugs visit the British National Formulary website: www.bnf.org

Q: Has anyone chosen to go with medication for their child? If so, what was the deciding factor? I'm trying to decide if this is the route I should take ...

A1: My son takes Risperidone and Valcote 250. This might be too much, but as he lives away from home we have to fight for every reduction like marines. The drawback has been the loss of a certain amount of intellectual skill but he doesn't hit himself so often and so hard, and he doesn't "rock & roll" the furniture when he gets angry. Take an active part in the research of which is the right one...

A2: We use Risperidone in small doses and this has decreased challenging behaviour. Found lots of opinions amongst professionals whether she should have it. They were reluctant to

give it at first...

A3: My 8 year old daughter is on medication – it was a hard decision but for the sake of my sanity I agreed a trial. She takes Equasym XL and Risperidone. She also needs Melatonin to help her sleep. This doesn't keep her asleep but gives me approx 2 hours relief. It's a hard decision but if they are not helpful or have too many side effects they can be stopped.

From the CBF: We endorse Shoumitro Deb's (2006): Using Medication to manage behaviour problems among adults with a learning disability (University of Birmingham) which states: "managing behaviour, involving medication or not, must always take place within person centred planning... all non-medication options should have been considered, and medication should be seen as necessary under the circumstances, or alongside non medication management."

Q: My son is on Risperidone to calm him down, but every morning he wakes up so angry. Have any other parents experienced any side effects with Risperidone? My son has taken to scraping his toes on the carpets and this is causing his nails and skin on his toes to bleed.

A1: Request an Occupational Therapist (OT) assessment from the Community Learning Disability team. Your son sounds like he is very sensory, and you need help and support to manage this. It sounds like you also need a podiatrist for his toe nails. The person who prescribed it may be able to offer an alternative.

A2: My son was on Risperidone for about 5 years, which helped other behaviours at the time. However when I took him off the difference in his temperance was remarkable: so much happier within himself. He still does a

lot of the same behaviours, but in a much happier manner.

A3: Are you sure he isn't waking up angry because of some sort of physical discomfort? My autistic adult son gets very angry and it is almost always because something somewhere hurts or feels different.

A4: My son put on over 30 lbs in weight in a month and developed stretch marks where his skin stretched so quickly. We have been fighting long and hard to get him off the drug because we felt that his behaviour was controlled better by using a very structured timetable using the TEACCH method. This has significantly reduced his aggressive behaviour and he is no longer in a secure environment but out in the community again.

From the CBF: The carer should be talked through the side effects of any medication and given written information to take away. Research suggests that a significant proportion of people with learning disabilities prescribed antipsychotic medication for behavioural reasons could have their drugs reduced or withdrawn (Ahmed Z et al, 2000)

What parents say



Oliver in one of the places he's at his happiest ... in his car!

Oliver is nineteen, and celebrated his birthday on a motor boat driven by his dad. Although special occasions generally mean very little to him (he hates any day that does not have all his usual routines) he really enjoyed the calmness of the river and the ripples on the water... and even more the massive portions of chocolate cake afterwards!

Oliver has severe learning disabilities and severe autism. He has no speech, but understands some basic words – even some Spanish, as he has been hearing Spanish since he was a baby. His communication is limited to pointing.

Oliver enjoys Disney cartoons (especially Jungle Book), being chased, and visiting his Spanish grandparents. Sometimes he can be very affectionate, and frequently very demanding, needing one-to-one attention most of the time.

Oliver has huge difficulties to cope with every day and his behaviour is often very challenging. As his mum I think he is an amazing young man to have adjusted to living with so many complexities and the very significant lifestyle changes he has experienced during his nineteen years.

• **Jayne Boulden**

Do you have a photo and story you would like to share? Please get in touch.

Want to join the debate? Membership of our email networks is free to both parents and professionals. Application forms from www.challengingbehaviour.org.uk or email info@theCBF.org.uk

New evidence

New evidence has called into question the generalised prescription of antipsychotic drugs for challenging behaviour.

The recent randomised controlled trial assessed whether antipsychotics do actually reduce aggression in challenging behaviour, in comparison to a placebo (a sugar pill).

Despite all treatments leading to a drop in aggression levels after the first week, the largest overall and consistent change was seen with the use of placebo medication, which showed the greatest reduction in scored aggression rates (79% vs. 57% for combined drugs)($P=0.06$). A separate analysis showed placebo was the most cost-effective treatment for aggressive challenging behaviour. No other positive effects were found for any of the active drugs in the other areas investigated.

These findings are especially valuable as antipsychotics in this complex population are susceptible to adverse side effects in common dosage. However, this research almost could not go ahead, due in part to the clinicians within the field of Intellectual Disability not putting patients forward. Many believed that the trial was a "total waste of time", confident that the drugs worked and that placebo would fail.

Whilst antipsychotics may be of value in some patients, further randomised controlled trials are still needed to help and protect these vulnerable individuals.

The reality of treating those with intellectual disability who display challenging behaviour is that there is no proven treatment, despite some clinicians' beliefs.

• **Sarah Dickens**, *Clinical Studies Officer, North London Hub, Mental Health Research Network, Imperial College.*

Read the full report:

Tyrer, P. et al. (2008): Risperidone, haloperidol and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: a randomised controlled trial. *The Lancet*, 371, 57-63.

My son and antipsychotic drugs

My son has a severe learning disability and has always had what we call 'temper tantrums'. He knows much more than most people give him credit for, but he is unable to express what he wants as his speech is limited and he has poor co-ordination.

He was first given an antipsychotic drug when he was in his twenties and living in a residential care home. Because I saw it was harming him I took him home and took him off it, much to his social worker's horror.

A few years later he was put on antipsychotic drugs once again. I was told when I queried it that it was to help him over the move from one home to another and that it would be temporary.

He is still on them and this is over twelve years ago now.

His psychiatrists have all advised me

that they can find no evidence of mental illness but feel they have to do something irrespective of the reason for his challenging behaviour. He is on chlorpromazine which I believe is the main reason he has put on so much weight that it now affects his breathing and his mobility.

more notice is taken of carers who have only known him six months than of me who has known him all his life.

The doctors do not listen to me when I tell them his behaviour is no better with drugs than without and it is affecting his health and mobility. I find that more notice is taken of carers who have only known him six months than of me who has known him all his life.

• **Gill Morton** (Mother)

PARENT PERSPECTIVES

Challenging the professionals

My son was prescribed an antipsychotic for occasional anxiety associated with autism.

I have challenged this decision because he appears withdrawn and lacks motivation and enthusiasm to do the things he usually enjoys and research on the issue convinces me that there is no credible evidence base for prescribing antipsychotics for non-psychotic conditions.

Despite all my efforts my son is still on

the medication with no sign of being taken off it.

I know that many parents and carers will be facing similar frustrations and difficulties and would ask anyone reading this who has had a similar experience to get in touch with the CBF.

Together we can take forward this issue – and hopefully get some resolution.

• **A concerned parent**

While this issue of 'Challenge' highlights the widespread use of mental health medication for people with challenging behaviour who have not been diagnosed with a mental health condition, it should also be noted that many people with learning disabilities DO have mental health issues which are often not identified. We are planning a future issue on this theme and would welcome your stories.

What to do

Families concerned about the use of antipsychotics in the treatment of their son or daughter should first discuss their concerns with the professional who wishes medication to be prescribed. Questions to ask could include:

- What is causing my son/daughter's challenging behaviour?
- What are the alternatives to medication for managing challenging behaviour?
- Does my son/daughter have a mental health problem?
- What evidence is there that this drug will reduce my son/daughter's challenging behaviour?
- Will you prescribe the drug for the purpose for which it is licensed?
- What are the possible side effects, and how will you monitor this?
- How will you monitor whether or not the drug is effective in reducing challenging behaviour?
- How often will the medication be reviewed?

Ask for a second opinion by a referral from your son/daughter's GP. Although there is no legal right to a second opinion, GPs rarely refuse.

Request a meeting to discuss in detail with a range of professionals involved in your son/daughter's care whether the medication is in your son/daughter's "best interests". If your son/daughter is aged over 16 and lives in England and Wales then any decision made on their behalf must be in their "best interests" as stated in the Mental Capacity Act.

Other options include:

- An independent advocate to support your son/daughter. Call the advocacy finder helpline: 0845 1 22 86 33.
- A mediation service (if available).
- In England discuss how to make a complaint with Patient Advice and Liaison Service (PALS). In Wales Community Health Councils (CHCs).
- Follow NHS complaints procedures
- Consult a solicitor about the possibility of asking the court of protection to make a judgement under the Mental Capacity Act.

Pica information sheet

It is estimated that between 4% and 26% of individuals with a learning disability display pica behaviour. The more severe the individual's learning disability the greater the chance, it seems, that they will display pica behaviour.

Pica refers to eating objects which are inedible such as stones, faeces, clothing and cigarette butts. Pica may be specific to just one inedible object or an individual may ingest a variety of different inedible objects.

While research into causes, assessment and interventions for pica

is extremely limited, the new Challenging Behaviour Foundation information sheet is based on the research available and current clinical practice.

The information sheet covers topics such as: What is pica? What causes pica? What are the risks? Assessing pica; Interventions for pica; What you can do

To order a copy of the new information sheet please see page 7. The information sheet is free to download from the CBF website: www.challengingbehaviour.org.uk

EXTRACT FROM OUR NEW INFORMATION SHEET

Pica behaviour: what can you do?

- Request a general health check from a GP to eliminate medical problems as the cause of pica
- Rule out iron and zinc deficiencies as the cause of pica by requesting a blood test from a GP
- Rule out mental health problems as the cause of pica by requesting a mental health assessment
- Ask your GP or social worker for a referral to a clinical psychologist or behavioural specialist for an assessment of pica behaviour and an intervention plan to help reduce or eliminate the pica behaviour
- A functional assessment is the most common assessment used to identify the causes of pica

Whilst you are waiting for an assessment and intervention/behaviour support plan to be put in place the following may be considered:

- As far as possible manage the individual's environment so that 'favoured' non-edible objects are out of reach/locked away.



Specialist equipment may be necessary such as virtually indestructible mattresses. Please see the Challenging Behaviour Foundation information sheet "Specialist equipment and safety adaptations" for more details.

- Keep a careful record of the person's attempts to eat inedible objects. What do they try to eat? Under what circumstances? This kind of information will be very useful to the assessment process

Extract from the new 'Pica behaviour' information sheet. Download from the CBF website www.challengingbehaviour.org.uk or see order form on page 7. Cost £1.00; free to families/ parent carers.

National Carers' Strategy

In February 2007 Gordon Brown announced that the Government would renew the National Strategy for Carers – its 10 year vision for improving support for carers. Due to be published as we go to print, copies can be obtained from the Department of Health website www.dh.gov.uk or the Department of Health publications orderline, telephone 0300 123 1002.

100 Club winners

Recent winners of the Challenging Behaviour Foundation 100 Club, winning £25 each were:

February 2008 – Mrs Glenda Akrill, Chatham

March 2008 – Mrs Carol Lowe, Middlesex

April 2008 – Mrs Jackie Cheeseman, London

May 2008 – Mrs K Dickens, Spalding

All proceeds from the 100+ Club help towards our office running costs. Shares cost just £1 per month. Please get in touch if you would like to join.

E-learning in positive behavioural support

New e-learning courses in Positive Behavioural Support covering the key elements of a quality service for people with challenging behaviour recommended in the recent Mansell report are now available. They result in nationally recognised BTEC qualifications and can be accessed from anywhere with an internet connection for £120- £190 for 150 - 200 hours of learning.

Contact Joanne.Wheeler@bromor-tr.wales.nhs.uk or telephone 01656 753849

Social Care Reform Consultation

Due to take place between May and November 2008, you can give your views on the reform of social care or find out more about the consultation by visiting www.careandsupport.direct.gov.uk or by writing to the Care and Support Team, Room 543, Richmond House, 79 Whitehall, London SW1A 2NS.

Supporters' News

While we cannot mention all our donors by name we would like to say a special thank you at this time to the **Womens Auxilliary League of the Licensed Trade**, Rochester, Chatham, Gillingham & Districts (£1,000), **1st Teynham Scout Group** (£130), **J Dowle Fencing & Garden Services Ltd** (£350), **Thomson Financial News** (£1,885) and all the friends and family of the late **Tony Martin** (£775).

Local Involvement Networks (LINKs): what, why and how?

LINKs are new consultation groups – a new requirement for local authorities following the recent Local Government and Public Involvement in Health Act.

All Local Authorities and Primary Care Trusts are now required to carry out a Joint Strategic Needs Assessment – one of the stated objectives being 'to identify groups where needs are not being met and that are experiencing poor outcomes' – with the long term aim being to influence and inform commissioning priorities.

You can help to make sure the needs



Thank you Freemasons

A big THANK YOU to the Freemasons Grand Charity for their recent fabulous grant of £12,000.

Michael Bailey, the Provincial Grand Master of the Province of East Kent, is shown here presenting the cheque to Karen McKane, CBF Development Manager (centre) and Gemma Honeyman, CBF Family Support Worker (left).

The grant from the Freemason's Grand Charity will support the work of the CBF's Family Support Worker, who runs the CBF parents linking scheme and email networks and provides individual telephone and email support to families. Gemma has also written our new Pica behaviour information sheet (see page 5).

Resource order form

Please note: 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**.

of children and adults with severe learning disabilities and challenging behaviour and their families are fed into this consultation process. Ask your local carers' centre, partnership board or special school how they will ensure the needs of this group are represented in your area.

Independent Living

Independent Living, a cross-government strategy about independent living for disabled people has now been published and is available from the Office for Disability Issues, www.officefordisability.gov.uk or telephone 0207 712 2845.

Distance learning opportunity

The School of Psychology, University of St Andrews is offering a distance-learning post graduate course for staff who have an undergraduate degree or professional qualification and work with adults with learning disabilities. The course lasts one year and comprises a choice of 4 modules from 6 (Challenging Behaviour, Mental Health, Profound and Multiple Disabilities, Offenders with Learning Disabilities, Older People, Vulnerability and Abuse).

For more information visit: <http://psy.st-andrews.ac.uk/people/personal/mc1/> or telephone 01334 462084

Have your say

We welcome articles from parents and professionals. Please get in touch if there is something you would like 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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	Cost	Number	Total £
CHALLENGING BEHAVIOUR DVD RESOURCES			
An Introduction to Challenging Behaviour: DVD	£31.50*		
What is challenging behaviour? Why does it happen? What can be done about it? Uses interviews with two parent carers, with specialist input from Peter McGill (University of Kent Tizard Centre). <i>40 minutes</i>			
Self-injurious Behaviour: DVD	£31.50*		
What causes self-injurious behaviour? What action should parents and carers take? Professors Chris Oliver and Glynis Murphy join forces with two family carers to offer clear and practical information and advice to families. A useful introduction also for professionals. <i>40 minutes</i>			
Communication and Challenging Behaviour: DVD	£31.50*		
Four family carers and a speech and language therapist explain the relationship between communication and behaviour and highlight practical approaches to improve communication and minimize challenging behaviour. <i>40 minutes.</i>			
CHALLENGING BEHAVIOUR INFORMATION SHEETS			
Pica behaviour (eating inedible objects)	All information sheets are available free of charge on the CBF website. To order by post please add £1.00 per sheet		
The use of medication in the treatment of challenging behaviour			
Basic information about challenging behaviour			
Getting a statement			
Communication and challenging behaviour			
The use of physical interventions			
Book list for parents / professionals (please specify)			
Specialist equipment and safety adaptations			
Functional Assessment (understanding the function of the behaviour)			
Self-injurious behaviour			
Psychiatric disorders in people with learning disability			
Health and challenging behaviour			
Parents' perspectives			
FULL INFORMATION PACK	£10.00*		
SUB TOTAL CARRIED FORWARD			

*Free to parents/unpaid carers. Prices include postage & packing in the UK only.

Registered charities: DVDs £16.50. Prices include postage & packing in the UK only. Videos also available – price £35.00 (£20 to registered charities). Please indicate clearly on the form if you require video format.

/ Continued overleaf...

SUB TOTAL CARRIED FORWARD			
PLANNING FOR THE FUTURE			
	Cost	Number	Total £
Planning for the Future: Introduction Information sheet	£1.00*		
Planning for the Future Information pack: Wales / Scotland / N Ireland / <i>(please specify)</i>	£10.00*		
Planning for the Future Information pack: England <i>Note: replaces our earlier Transition & Adult Options information packs – content remains the same</i>	£10.00*		
Challenge: Spring 2008 special issue <i>while stocks last</i>	FREE		
A New Pathway: DVD DVD overview of the Medway Challenging Behaviour FE service. <i>20 minutes</i>	£5.00*		
A New Pathway: Report A review of the planning model used to develop the Medway Challenging Behaviour FE service. <i>40 pages</i>	£ 5.00*		
DONATION – please consider a donation to support our work. Thank you			
TOTAL			

*Free to parents/unpaid carers. Prices include postage & packing in the UK only.

All proceeds go towards helping families caring for individuals with severe learning disabilities and challenging behaviour. Thank you for your support

Gift Aid means we can claim back the tax on your gift (25p for every £1 you give) at no extra cost to you. If you are a UK tax payer and would like to Gift Aid your donation, please sign here:

Parents/ family carers please note: while we are happy to send you our resources free of charge, if you can afford to send a donation this will help us to provide free resources to other families. Thank you.

Please indicate if you are a parent or unpaid carer. If you are a registered charity please give your charity registration number:	
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Name

Organisation

Address

Postcode

Telephone

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.

You can keep informed about new resources through our free newsletter, three times a year. If you do NOT want to receive this, please tick here

If you would like to support the CBF regularly please tick here to receive a standing order form

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

Thank you for your support

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 support families and professionals across the UK – with just three full time members of staff!*
- *We do not charge parents for services or resources*
- *To keep costs down much of our work is carried out by volunteers.*
- *If everyone reading 'Challenge' gave just £15 a year we would have a guaranteed income of over £25,000, which would enable us to take forward a number of important projects*
- *Regular giving by standing order makes your money go further by keeping down administrative costs.*
- *Your support really would make a big difference to us!*

Please consider how you could support our work.

The Challenging Behaviour

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