

Kent Academic Repository

Full text document (pdf)

Citation for published version

Osgood, Tony (2011) A Pannacotta Fable. . pdf newsletter.

DOI

Link to record in KAR

<http://kar.kent.ac.uk/33594/>

Document Version

Publisher pdf

Copyright & reuse

Content in the Kent Academic Repository is made available for research purposes. Unless otherwise stated all content is protected by copyright and in the absence of an open licence (eg Creative Commons), permissions for further reuse of content should be sought from the publisher, author or other copyright holder.

Versions of research

The version in the Kent Academic Repository may differ from the final published version.

Users are advised to check <http://kar.kent.ac.uk> for the status of the paper. **Users should always cite the published version of record.**

Enquiries

For any further enquiries regarding the licence status of this document, please contact:

researchsupport@kent.ac.uk

If you believe this document infringes copyright then please contact the KAR admin team with the take-down information provided at <http://kar.kent.ac.uk/contact.html>

Challenge



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

Spring 2011

The newsletter of the Challenging Behaviour Foundation

False economy

We all know about the state of the economy and the need to curb spending.

But simply deciding to spend less on what is needed is not the answer.



Vivien Cooper

An opportunity to check that money is being spent wisely

We need to look at what is required, what isn't and what can be changed. It is also an opportunity to check that money is being spent wisely. However, there seems to be a blanket mentality: "the cost of your son's service will be reduced by 28% to reflect the cut in funding to the Local Authority" or "your Direct Payment will be cut by 40%". Not only is this not legal (there cannot be a change to support provided to meet an assessed need unless the need has been re-assessed and has changed), but it is not sensible.

A person who has complex needs is likely to have a complex support package – which in turn is likely to be relatively high cost. Working out whether this is good value for money requires people who understand what a good support package (and good outcomes for the individual) looks like.

Leaving aside the impact on the individual, is this good economic sense?

At the CBF we provide support to individuals in a range of situations. Recently, a number of family carers who have set up and currently manage complex individualised packages of

care for their relative have been targeted for cuts - despite the fact that the support provided delivers a good quality of life for the individual, and financially compares very favourably to any credible alternative. In direct contrast, another family finds their relative placed in a private hospital, at very high cost, where

their needs are clearly not met and yet they are unable to persuade the funding authorities to develop a more personalised solution. Families are having to resort to legal interventions – surely not a situation anyone would suggest is positive. Leaving aside the impact on the individual, is this good economic sense?

Now is surely the time to focus on and invest in what works

Failing to meet the needs of a person with severe learning disabilities whose behaviour is described as challenging is costly on all fronts: to the person, their family, the local authority and the NHS. Instead of focussing on short term savings (which will lead to longer term higher costs) now is surely the time to focus on and invest in what works – early intervention, a holistic, person-centred approach and quality individualised support and services.

• Vivien Cooper

Chair of Trustees and Founder of the Challenging Behaviour Foundation

PAGE 2

A Pannacotta Fable

Get people hooked, they keep on buying the product...

PAGE 3

Night to remember

I scanned the room and then I saw him...

PAGE 4

Parents' perspectives

Peter was left to bang his head for hours...

PAGE 6

Getting around

Government ministers have no understanding of the devastating impact this decision will have...

PAGE 8

MPs challenged

We would like to thank the following MPs who have already signed up to the Charter...

'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

A Pannacotta Fable

I'm increasingly spending time with people whose experience of social services, health, education and adult services is nothing less than, well, to be frank, appalling.

These anecdotes of heartache and woe, of anger and frustration, of not being respected by the system or dignified by being heard; these individual notes seem to combine to create a Greek chorus of exasperation: *This is not what we need.*

I even find the same or similar sentiments voiced when I explore with professionals why things cannot be delivered, why options are so sparse, why promises are broken. Many professionals and providers feel things are out of kilter: *This is not what I trained for.*

It seems most people involved are sick of what might be termed the malnutrition of support, and the rich food of rhetoric has not landed on people's plates. Everyone is starving for honesty.

A few years ago my wife and I developed a dangerous taste for pannacotta, that creamy vanilla pudding, heavy with sugar and lusciousness. We usually made it ourselves but when time was short we'd buy a particular brand. (This was

shortly before we both mysteriously gained a lot of weight). We bought pannacotta for several months. Then it became a bit bland. It must have been us. We had become satiated, surely. But when checking the ingredients (sad, I know) we noticed how constituent parts had been altered, the cream reduced, the vanilla superseded by vanilla-flavour, the sudden appearance of skimmed milk and guar gum. A different thing. This process of watering down, of economising, is called without a trace of irony, *refinement.*

People buy the memory of what the product once was

Food companies and branding gurus know something interesting. Get people hooked, they keep on buying the product, and even when you water down the ingredients, people keep purchasing it. Because in effect people buy the memory of what the product once was. Everyone knows the idea of The Net: social and health care in the UK.



This fairness is what our grandparents fought for. When it was new the net was intended to catch many. Then the net was stretched. Oh, there's always a rationale. A new economics. But look, there's still a net.

Once the holes became stretched then aspirations and intents oozed through, a few people tumbled down. People who didn't quite fit the net design.

Look at all these human lives, falling from great heights

We've stretched our web wide over the years when times were tough and it seemed to many there were more holes than net. Look at all these human lives, falling from great heights.

Please stop refining. Stop diverting us from seeing the reality by waving in front of us carefully crafted images of the memory of what we once loved. That is not what we need.

How big do the holes have to be, how many people must fall through these holes, before we wake to the fact there is no net?

• **Tony Osgood**

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

HOW YOU CAN HELP

With our work ever increasing and with a number of major grants shortly coming to an end we will need to work even harder this year to raise the funding we need. In the current economic climate we need your support more than ever to help us continue our work. Here are some of the ways you can help...

DONATE ONLINE: If you are organising a fundraising event, gifts in memory of a loved one, or if you want to make any one-off or regular donations, go to www.virginmoneygiving.com and search for Challenging Behaviour Foundation, or use the links on our website: www.challengingbehaviour.org.uk

DONATE BY PHONE: The CBF is now able to accept credit or debit card donations. Simply call the CBF office (01634 838739) with your card details.

TELL US YOUR EXPERIENCES: If the CBF newsletter, resources, telephone or email support have helped make a difference to your life or the life of someone you care for please let us know. All such 'evidence' is important to help us make the case to secure more funding to continue our work.

THANK YOU FOR YOUR SUPPORT

Q: My son has received Direct Payments for the last 4 years. I have always had problems with the people I employ to support him, despite my very best efforts. Any ideas?

A1: I have been using Direct Payments successfully for the past three years. I got my carers through word of mouth, and both have been very good. Perhaps you could try placing notices in special schools to see if some of their staff are interested?.

A2: I have found it really useful to sit down with new employees weekly and have a feedback session: What happened? How did I deal with it? How should I have dealt with it? These build up relationships over time

A3: I have to say that ours is a

particular success story, but we have worked at it! We have two full time employees, both the same age as our son. It is so much better when our son goes out with a 'peer'.

A4: My advice would be to keep on persevering. With Direct Payments care is in place that your son controls, rather than for him to be given a "one size fits all" service, when it actually doesn't fit all! I have also always found that the best carers are the ones who have empathy.

A5: My son has been on Direct Payments for about six years and we have been very lucky. The job centre run a 'back to work' scheme where they will pay half of a person's wages for a six month period. This works in your favour because it is a trial period. I have always found local disability organisations good because they are doing it because they want to, and not necessarily because it is a job.

Q: My daughter is seven and we have a huge problem with her smearing. If you do not catch her in time she has it everywhere. I am at my wits end - does this get any easier in time?

A1: We took our son (then aged 11) to a bedwetting clinic, which was very helpful. The doctor there had seen many children like ours, and advised us on toilet training. We gradually increased the time spent on the toilet and used huge amounts of positive reinforcement if the toilet was actually used. My son is now 21 and I can confidently say it hasn't happened since he was 17, and was no longer a problem well before that.

A2: We found that reacting in a monotone, how-boring-you-are way worked and the smearing became

less frequent. So the answer is yes, they do grow out of it, it just doesn't seem as if they ever will.

A3: For the time being get vinyl flooring to replace carpet, washable curtains and wipeable chairs. It all helps.

A4: We found the solution for us was to put a little bit of toilet paper in the pan to stop most of the splashback. A couple of squares is enough.

A5: My daughter who seems very similar has started putting her toys down the toilet then poo-ing on them. She recognises that the toys need to be cleaned because if not watched she will pull them out and put them in places she thinks will help clean them. Once I found a couple of them, well soiled, in the kettle - she was boiling them. Never looked at that kettle again and felt 'time for a cup of tea'....!

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

Night to remember



The music throbbed. The lights flashed. The dance floor was heaving. I scanned the room and then I saw him. The most handsome man there.

Our eyes met only briefly but his radiant smile remained as I walked towards him. I danced his dance. We stilled, we rocked. I squeaked with his squeaks. He held my hand. **HE HELD MY HAND!!!**

I felt we were the only two people there. Worries forgotten as we lived in the moment. I felt connected!



Did I mention he held my hand!!!

....The evening was then cut short as C's staff had to take him back (end of shift). But it was a magical night - C's night club debut, one I will remember for a long time.

• **Jen Fookes**, family carer

Read more of Jen's blog at: <http://motherofshrek.blogspot.com>

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

From pain to laughter



Peter

My son Peter used to live in a residential school. It was not a light hearted decision for him to go as we lived 180 miles away. We visited regularly and brought him home when we could.

Whilst at the school Peter was left to bang his head for hours at night, he slept on the floor and was hurt by other residents, despite having 2:1 support. Peter stopped eating and grew horrendously thin and had a huge pressure bruise on his back. We visited twice a week, and asked staff to record what he was eating - it showed days with nothing or very little and Peter continued to deteriorate.

After an 'I can't cope' call from staff, my new husband, sons and I decided to bring Peter home for good. The four of us worked 2:1, 24 hours a day - with two of us working full-time to earn money. We used communication, intense support and drama. Peter made progress and with the right support he improved incredibly.

As the head hitting reduced slowly, skills that he'd lost came back and I remember a friend coming to the house, standing at the gate and saying in amazement, 'he didn't hit his head!' It suddenly dawned on me how far we had come.

Now my house sometimes rings with laughter - and not only do I love my son, I actually like him sometimes too!

• **Julie Maidens**, family carer

A guide for everyone

• *"An exceptionally useful resource bringing together a wide range of important information in a very clear way..."*

• *"The CBF has done an excellent job in compressing the relevant information into such an accessible document..."*

• *"I read the first few pages and cried... I have always advocated that my sister is a person first, just the same like anyone else and should never be defined through her behaviours. ... Thank you for giving others and me hope for their loved ones"*

• *"first class, easy to read, and - I think - essential not only for advocates but for family/ carers/ staff well done"*



A guide for advocates
Supporting people with learning disabilities who are described as having challenging behaviour



We are delighted with the feedback received on our recent publication: 'Supporting people with learning disabilities who are described as having challenging behaviour – a guide for advocates'.

• **David Thompson**, Senior Practice Development Manager at the Social Care Institute for Excellence, writes:

People have different ideas about who are the advocates for people with learning disabilities. Some people may be able to advocate for themselves (self – advocates). Parents, other family members and sometimes friends can be great advocates ensuring the person gets the support they need. The same can be true of some professionals and paid carers. Then there are people whose job title is 'advocate' who may be paid or volunteers, including new special types of advocates who have roles set in law (Independent Mental Capacity Advocates, and Independent Mental Health Advocates). You might even come across a carer's advocate whose job is to support family carers get the services they and their relative need.

I hope all advocates of people with challenging behaviour get hold of a copy, not just the paid ones

The CBF's new guide is an exceptionally useful resource bringing together a wide range of important information in a very clear way. I especially like the checklists which will quickly help identify what areas of a person's life could benefit from extra attention. I hope all advocates of people with challenging behaviour get hold of a copy, not just the paid ones. I am sure that family members, professionals and paid carers will find it to be a great help in making sure that people are getting the best possible support.

'Supporting people with learning disabilities who are described as having challenging behaviour – a guide for advocates' is available from the CBF, price £16 (free to family carers). Please use the order form on the back page. Telephone orders and payment by credit/debit card now also accepted (3% card handling charge).

Support for families

The Challenging Behaviour National Strategy Group (CB-NSG) has been working with the Social Care Institute for Excellence (SCIE) to let carers know what services and support should be available to children and adults with behaviours that challenge.

At a time when many local areas are having to reduce the support they can offer, it is particularly important that people are aware of what services they should expect to receive. The CBF and SCIE are producing three 'At-a-Glance' guides so families know what they are entitled to, and can be confident when asking for it.

The three guides are aimed at family carers supporting people at different ages: families of children, families supporting a teenager through transition, and family carers of adults.

The key message for all age groups is the same: that people with behaviour that challenges have a right to good quality, multi-disciplinary support, and their families are expert partners who need to be listened to, and supported in their own right. Timely interventions from skilled practitioners can help reduce or avoid challenging behaviour.

The guides will be formally launched at the next meeting of the CB-NSG in March 2011, and will be available to be downloaded from www.scie.org.uk and www.challengingbehaviour.org.uk, or ordered in hard copy from hugh.constant@scie.org.uk or info@theCBF.org.uk. The guides are free.

• **Hugh Constant**, *Practice Development Manager, SCIE*



EXTRACT FROM OUR NEW RESOURCE

Getting the right support

This 'At-a-Glance' briefing is for family carers supporting an adult with severe learning disabilities and behaviour described as challenging. It will help you understand what you should expect from local services.

The way things are done will vary between different areas. There is information at the end about what to do and who to contact if you are concerned that your family's needs are not being met.

Key messages

- Challenging behaviour can usually be reduced or avoided with support.
- Support should be flexible and personalised to the needs and circumstances of individual families.
- Support should be available to prevent challenging behaviour developing or getting worse.
- Government policy is clear that adults with learning disabilities have the same rights as everyone else.
- Support should be available from a behaviour support team or equivalent.
- A comprehensive behaviour assessment should include: a functional assessment of behaviour, medical health check, mental health check, communication assessment and social and environmental factors that may affect behaviour.
- A behaviour support plan should be developed, setting out what is likely to trigger the behaviour and how families and services should respond.
- Families should expect wherever possible to work in partnership with the professionals involved with their family members' care and support



Real jobs



Frank Proctor

The Department of Health (2001) estimated that less than 10% of people with learning disabilities in the UK have jobs. However, for people with complex needs (including

people with profound and multiple learning disabilities, people with learning disabilities/ significant mental health problems and behaviour that challenges or offending histories) the number in paid employment is even lower.

The Sustainable Hub of Innovative Employment for people with Complex Needs (SHIEC) was set up in 2010 to reach out and support genuine paid employment for individuals who have a learning disability and complex needs and who find themselves furthest from the job market.

The project is working with service providers in the South East and across the UK to identify people with complex needs, assist them in finding and maintaining paid employment and share the learning. Forty individuals have been identified, vocational profiles are being completed and potential employers are being contacted.

For some involved in the project, paid employment has begun and is providing important learning. So far the biggest challenge has been in changing peoples' attitudes and expectations. In the coming months we will continue to support people to find and maintain paid employment and will evaluate the project in order to share the learning.



Rhea Young

- **Frank Proctor**, *Project Manager* &
- **Rhea Young**, *Research Assistant*

For more information contact Frank Proctor: frank.proctor@theCBF.org.uk or 07738 152602

Getting around



Thomas

Our son Thomas lives in a residential placement about 75 miles away from our family home. We cannot reach it by public transport and our son is unable to access public transport because of his unpredictable behaviour.

In the budget it was announced that Mobility Allowance for those who live in residential placements or colleges would be cut.

It is not easy for those with challenging behaviour to be granted this benefit. We had a lengthy battle to obtain it for our son (now 25). Without it those affected will have to fund their transport from the £21.40 a week allowed for "luxuries", which already includes clothing, toiletries, gifts, holidays and entertainment. The result will be that they will be unable to afford a trip of any sort and will in effect be "prisoners for life".

Our son needs to travel in a large reliable vehicle where he cannot reach the driver, accompanied by two carers. The removal of his mobility allowance would mean that he would be hard pressed to fund essential visits to doctors, dentists etc let alone any other activity. As he cannot read, watch TV or in any way occupy himself and is a healthy strapping young man, he needs to get out for walks in the country, swimming, etc as well as maintain links with his family.

Government ministers have no understanding of the devastating effects this decision will have.

I feel let down by the promise to "protect the most vulnerable in our society". Furthermore it is a breach of my son's basic human rights.

• **Margaret Haycox**, family carer

Protecting t

Anthea Sully from the Learning Disability Coalition examines the government's Comprehensive Spending Review.



Anthea Sully, Learning Disability Coalition

The Comprehensive Spending Review, which sets out the Government's spending commitments for the next four years was published by Chancellor George Osborne last October. The emphasis was on ensuring that the UK's deficit was reduced, which the Chancellor said required big cuts to public spending. There were three principles behind the spending review: 'reform' (to ensure an end to waste), 'fairness' (in ways affordable to taxpayers) and a focus on 'growth' (investments in areas most likely to achieve growth).

We are still learning how the announcements in the spending review will affect services

It had been clear for several months that cuts were on the way but we are

still learning how the announcements in the spending review will affect services. It will be important to demonstrate what fairness looks like for people with learning disabilities when making the case to protect funding.

This does not always result in the fairest solution for everyone

The Government has made clear its intention towards moving power down to local level in its localism agenda. This, combined with the de-ringfencing of several pots of money, gives councils far more say in the way in which money is spent. Whilst this means that councils have more flexibility in how they meet local needs, the huge financial pressures facing councils means that this does not always result in the fairest solution for everyone. For example, the Supporting People grant has already been de-ringfenced. In many places such as Cornwall this has resulted in cuts for people with a learning disability as councils have spent the money elsewhere. This is a major source of concern for the future, especially as the money given from central to local government is going down 7.1% per year for each of the next four years.

The total health budget will be protected, and linked to a series of reforms designed to increase productivity, cut out waste and give better value for money. An additional £1 billion will also be made available for social care through the NHS, as part of an overall extra £2 billion for social care. We don't yet know, when this money will be available. In social care there is a commitment to expansion of personal budgets with these being established for children with special educational needs, children with disabilities and those with long term health needs. There will also be an extra £1 billion in grant funding by the fourth year of the spending review and £1 billion to encourage joint working between the NHS and local authorities. Encouraging the NHS and local authorities to work together will be of particular benefit to people with profound and multiple learning disabilities. Whilst the additional funding sounds a lot it remains to be seen how much is new funding and whether it can meet the known increasing demand for services.

One of the biggest areas for cuts was in welfare payments. Child benefit will be cut to families where a parent earns more than £44,000 per year. This could have an adverse effect on parents of disabled children as it does not take into account disability related expenditure.

he frontline

ness the impact on individuals with learning disabilities of

Another cut announced is the intention to remove the mobility component of the Disability Living Allowance (DLA) received by 380,000 residents who live in care homes. This cut has sparked a major campaign as this money enables disabled people to get to the shops or visit their families. This proposal has been presented by the Government as 'aligning the policy' with hospital admissions. However there is clearly a major difference between receiving hospital treatment as an in-patient and living in residential care.

There are significant changes to the way that the Employment and Support Allowance is being delivered and the way applicants are assessed through the Work Capability Assessment. This is currently being reviewed by Professor Harrington. At this stage it is unclear how many people with a learning disability will be affected by these changes and what impact it may have.

The announcements regarding housing are likely to make it increasingly difficult for people with a learning disability to find suitable housing they can afford

The announcements regarding housing in the spending review are likely to make it increasingly difficult for people with a learning disability to find suitable housing they can afford; effectively 'shutting the door' for people to live more independently. More positively, the Emergency Budget introduced an allowance for disabled people who need extra room for a live-in carer.

It remains to be seen what the impact of the move towards the 'Big Society' will be. The Government will direct money to support capacity building in the voluntary and community sector, including an endowment fund to assist local voluntary and community organisations. Whilst developing the voluntary sector would seem to be a laudable aim we are already seeing a reduction in local authority funding to advocacy and advice groups and there are very real fears that family carers will be expected to manage in very difficult circumstances.

It is more important than ever that we make sure politicians and other decision makers understand how vital social care support is to people's lives

The members of the Learning Disability Coalition first came together in 2007 to fight against the cuts in social care that were already happening. Now in 2011 it is more important than ever that we make sure politicians and other decision makers understand how vital social care support is to people's lives. We will continue to make the case to 'protect the frontline' so that as budgetary decisions are made support for people remains a top priority.

To find out how you can campaign in your local area visit: www.learningdisabilitycoalition.org.uk or call 020 7696 5574 or e-mail: ldc@learningdisabilitycoalition.org.uk

• **Anthea Sully,**
Learning Disability Coalition



Anthea and friends

A home of my own

The spending review announced changes in housing that will affect people with disabilities. The impact of the changes are summarised here.

Private rental

Good news - the introduction of an additional bedroom where a disabled person requires a non-resident overnight carer. However, other changes are likely to restrict choice of where to live, creating difficulties for people who need housing in specific areas. The introduction of absolute caps (eg. £290 a week for a 2 bedroom property) and the reduction of the Local Housing Allowance (LHA) will have an impact.

Discretionary Housing Benefit

This can be used to make additional payments when rent is higher than Local Housing Allowance (each local authority makes their own decisions on eligibility – new guidance due soon). People with a disability (in receipt of mid rate Disability Living Allowance or severe disability premium) will be entitled to the one bedroom property Local Housing Allowance rate (from April people under 35 are only eligible for a single room in a property rate).

Social Housing

Despite great demand there will be a 60% cut in funding for building social housing. The Homes and Communities Agency is due to launch the Affordable Housing Programme.

Shared Ownership

Support for Mortgage Interest is reduced from 6.08% to 3.68% bringing the scheme which enabled people with long term disabilities to part own their own house to a halt. The main lender has suspended the mortgage product used, which had enabled people with no deposit and on benefit only income to take on an interest only mortgage over 25+ years. Future shared owners will need a substantial deposit, earned or other income streams. Negotiations continue to find alternative ways forward.

Further information on housing choices can be found at <http://www.valuingpeoplenow.dh.gov.uk/valuing-people-now/housing> or <http://www.housingoptions.org.uk/>

• **Karyn Kirkpatrick,** *Valuing People Now National Housing Lead*

MPs challenged

Despite the arctic conditions in much of the country the Challenging Behaviour All Party Parliamentary Group meeting at the Houses of Parliament went ahead on 1st December 2010. A packed audience listened to the real life experiences of family carers Vivien Cooper and Linda Woodcock.

Dr Roger Banks emphasised the rights of the child and the rights of disabled people, discussing the importance of sustaining these principles which are often compromised when a person's behaviour is viewed as challenging. For example, the right of children and young people to grow up in a family environment is often undermined by a lack of specialist services in the local area, which means that children and young people with behaviour that challenges are often forced to move away from their family setting.

Following the meeting at Westminster, the Challenging Behaviour Foundation has written to all MPs requesting that they sign up to the Challenging Behaviour Charter and ask their Director of Children's services six questions about local support and services for families.

We would like to thank the following MPs who have already signed up to the Charter:

- **Gordon Henderson** – MP for *Sittingbourne and Sheppey*
- **Julian Huppert** – MP for *Cambridge*
- **Steve McCabe** – MP for *Selly Oak, Birmingham*
- **Grahame Morris** – MP for *Easington*
- **Caroline Nokes** – MP for *Romsey & Southampton North*

You can help by asking your MP to sign up to the Charter to support the rights of children and adults with learning disabilities and behaviour described as challenging. If you're not sure who your MP is you can find out at: www.parliament.uk/mps-lords-and-offices/mps

To receive free e-mail updates on the work of the CB-NSG e-mail: nationalstrategygroup@theCBF.org.uk with "Associate member" in the subject title.

Minutes of the APPG meeting are available from Peter Hand: Peter.Hand@mencap.org.uk

Better health: better lives

There are an estimated 5 million children and young people with intellectual disabilities in Europe. While many of them live healthy and fulfilling lives with their families, a significant proportion suffer as a result of violations of their human rights to grow up in a family, to have good health and to realise their maximum potential free from harm and abuse.

In some countries many children are still being admitted or abandoned to long term institutional care, but even where such care is no longer supported, they are subject to inequalities in access to health care and treatment, segregation in education and in communities and are more likely to grow up in conditions of poverty and deprivation.

I have been involved in the drafting of a new European declaration: Better health, better lives: children and young people with intellectual disabilities and their families.



Dr Roger Banks at the signing of the declaration in Bucharest



Children in an institution

The declaration covers 4 key objectives:

- promoting and supporting good physical and mental health and well-being;
- eliminating health and other inequalities and preventing other forms of discrimination, neglect and abuse;
- providing support that prevents family separation and allows parents to care for and protect children and young people with intellectual disabilities;
- supporting children and young people in the development of their potential and the successful transitions through life.

These aims are outlined in 10 priorities and a related set of actions.

This initiative was led by the World Health Organisation in partnership with UNICEF and was signed by representatives of European member States in Bucharest in November 2010.

- **Dr Roger Banks** *FRCPsych FRCGP(hon) Consultant in the Psychiatry of Learning Disability, Betsi Cadwaladr University Local Health Board, Wales
Honorary Senior Lecturer, Bangor University*

Details of the Declaration, Action Plan and a set of accompanying expert papers can be found at:

<http://www.euro.who.int/en/what-we-do/health-topics/diseases-and-conditions/mental-health/activities/intellectual-disabilities>

Action: Send us your experiences

The CBF will be collating a response to the World Health Organisation. If you have stories (good or bad!) relating to any of the four areas listed above, please send these to: info@theCBF.org.uk or telephone 01634 838739

Making the case for early identification & intervention

Challenging behaviours in people with intellectual disabilities have a high impact in clinical, social and financial terms. These behaviours are fairly common and therefore represent a significant test to educational, health and social services. Despite the availability of effective evidence-based interventions (see box), these interventions are rarely available in practice or are provided too late (eg. when people are adult and have been displaying challenging behaviours for many years), or under conditions that are likely to reduce their impact (eg. less than optimum service environments or by carers with insufficient training)

There is however evidence that behavioural intervention can be successfully delivered at an early age when theoretically challenging behaviours will be most responsive to change by parents and other carers (such as teachers).

Although more research is required, an increasing number of studies demonstrate that early behavioural interventions by parents and other carers can have significant beneficial impacts both in terms of reducing childhood challenging behaviour and improving parental mental health and family functioning.

The often significant costs of supporting people who challenge over the course of their lives partly reflect the costs of failing to effectively intervene at an early stage. Early intervention should mean that many children who display early signs of challenging behaviour could be diverted away from developing more chronic and persistent forms of behaviour. Investment in well-developed early intervention programmes is therefore likely to yield substantial cost savings in the longer term.

• **Professor David Allen**

Associate Clinical Director, ABMUHB & Professor in the Clinical Psychology of Intellectual Disabilities, Cardiff University

To read the full report visit: www.challengingbehaviour.org.uk

The evidence

A series of studies have identified that behavioural interventions can produce significant intervention effects across:

- different service user groups (e.g. both those with mild and more severe intellectual disability, people with autistic spectrum disorders)
- different types of challenging behaviour,
- increasingly severe forms of challenging behaviour
- across the age span.

As well as impacting on challenging behaviours themselves, there is emerging evidence that positive behavioural interventions can improve the quality of life of the people concerned and reduce, for example, amounts of psychotropic medication received. Despite evidence of effectiveness, the use of such interventions within the UK is very limited. In contrast, the use of non-evidence based procedures (such as psychotropic medication and restraint) occurs at high rates.

Research has also indicated that there are a range of personal characteristics that act as “risk markers” for the development of challenging behaviour. These include:

- Being male
- Having more severe intellectual disability
- Having additional secondary disabilities (notably in the form of communication and mobility), sensory and physical impairment
- Delays in either expressive or receptive communication
- Having a diagnosis of autism
- Having certain genetic conditions associated with intellectual disability such as Lesch-Nyhan and Cri-Du-Chat syndrome.

Better commissioning

“Developing better commissioning for individuals with behaviour that challenges services – a scoping exercise” has been published by the University of Kent Tizard Centre and The Challenging Behaviour Foundation.



There are a number of continuing problems faced by people with learning disabilities whose behaviour presents a challenge including breakdown of community placements, increased use of out-of-area placements and the persistence of poor quality institutional solutions.

The report identifies key findings from interviews conducted with commissioners and family carers. Families identified and requested support and services early, yet it was only when they had reached crisis point that adequate services were offered: “I had a breakdown in February and this is when everything changed for my son... and this is the reason why at the moment he is in residential care. If we were getting the help that we needed earlier things might have been different.”

The report makes a number of recommendations including:

- The development of a programme of nationally coordinated work to support a number of local commissioners (in every region) to implement existing guidance and particularly to intervene earlier with challenging behaviour and mental health problems.
- The Challenging Behaviour National Strategy Group (CB-NSG) should continue to co-ordinate and drive the process of improving the quality of outcomes for individuals whose behaviour challenges and their families.
- The Department of Health should review the application of continuing care criteria in order to clarify the reasons for the wide variation in numbers between areas with a view to reducing perverse incentives.

The report is available to download from the CBF website: www.challengingbehaviour.org.uk

Fair Society?

If you are worried about cuts to services for disabled people, you may want to join The Campaign For A Fair Society. The campaign is not just about protest, but also about making a positive contribution, seeking to engage policy makers in dialogue. To join The Campaign For A Fair Society, and find out more about the principles it promotes, visit www.campaignforafairsociety.com

Cemented to the floor by law

This paper, subtitled 'Respecting legal duties in a time of cuts', outlines the central legal duties in relation to disabled children and their families with which public bodies must comply. Given the increasing realisation of the damage the current spending cuts are likely to do to disabled children's services, an understanding of what the law requires in this area is more important than ever. The paper sets out some of the most important legal duties to consider when funding decisions are being taken.

Available from [www.ncb.org.uk/cdc/resources/cemented to the floor by law.aspx](http://www.ncb.org.uk/cdc/resources/cemented%20to%20the%20floor%20by%20law.aspx) or <http://snipurl.com/1vwcip>

IN SYMPATHY



Neil Chambers 15.11.70 - 9.8.2010

Jane and David Chambers write: "Our 39 year old son Neil, who was classically autistic, died suddenly and unexpectedly in August after a traumatic fall following an epileptic seizure. Having been previously excluded from two residential homes, Neil enjoyed 6 ½ years living on his own in a small privately rented house with garden, with 24 hour support workers. He had always shown an interest in food preparation and cooking while at home with us and this continued in his own home. He enjoyed walking and being outside and had an hour's walk daily around the fields and footpaths near his and our homes... We have received useful information from CBF and wanted to support you with a donation in Neil's memory to help other families who have similar problems."

Our sympathy goes to Jane and David at this difficult time, and our thanks for the £500 donation received in his memory.

SUPPORTERS' NEWS



Neil, Sophie and Sam at the University of Kent Volunteering Fayre

A thank you to our young volunteers

A big thank you to Sophie, Neil and Sam who all regularly help the CBF in various ways from fundraising to coming into the office to help with newsletter mailings. The three young volunteers recently attended the University of Kent Volunteering Fayre on behalf of the CBF to help recruit volunteer advocates. We really appreciate everything you do and have done over the years. THANK YOU!

Recent donations

While we cannot mention all our donors by name we would like to say a big thank you at this time to **Pennine Camphill Community**

(£50 donation) and the **Medway Dental Public Health Team** - £125 donated "rather than buying Christmas cards and gifts for one another."

Thank you also to the family and friends of **Mrs Katie Fair**, long time supporter of the CBF, for their donations to the CBF in her memory, totalling £330. Our sympathy goes also to the family of **Mrs Audrey Day**, and our thanks for their kind donations totalling £220. "Audrey was greatly impressed with what Vivien achieved and always supported the CBF."



Audrey Day

Finally, we are delighted to report that the CBF was recently awarded a fantastic £20,000 by the **Freemasons Grand Charity**. This funding has been awarded specifically to go towards the salary costs of Gemma Honeyman, our Family Support Policy Officer. The post of Family Support Policy Officer was created at the CBF to combine giving practical support to families with collating data from families to inform the CBF's national strategic influencing work on behalf of individuals whose behaviour is described as challenging.

The Freemasons have been particularly generous to the CBF over the years, supporting us with £12,000 back in 2008. We know how hardworking and generous individual masons and Masonic lodges must be in order to raise these kinds of funds. If you are a Freemason – thank you! And if you know anyone who is a Freemason please be sure to pass on our thanks and appreciation – without this support we wouldn't be able to continue our work.

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**.

CBF on Twitter

The Challenging Behaviour Foundation is now on Twitter. You can follow us at <https://twitter.com/CBFdn>

Mental Capacity Act – Free training

Free events to launch new resources around understanding the Mental Capacity Act for relatives of people with learning disabilities aged 16 and over, and those who support them are being held in Birmingham (14th April) and Bridgwater (26th May). For details email holly.osullivanjones@hft.org.uk or telephone 0117 9061751.

100 Club Winners

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

October 2010: Robert Howard (St Albans, Herts)

November 2010 (special £50 prize): Lyn Walton (Gillingham, Kent)

December 2010: Catherine McIntosh (Gillingham, Kent)

January 2011: Simon Ingarfield (Maidstone, Kent)

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

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.

© The Challenging Behaviour Foundation. All rights reserved.

| | 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 & 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 – Supporting Change: DVD | £63.00* | | |
| In this 2-disc DVD set meet Oliver, Dougie and Dominic and hear the functional assessment process explained. Interviews with family carers highlight the range of causes of challenging behaviour, and how a functional assessment can help put in place appropriate behaviour management strategies for individuals with severe learning disabilities. <i>(Approx 70 mins)</i> | | | |
| CHALLENGING BEHAVIOUR INFORMATION SHEETS | | | |
| Basic information about challenging behaviour | All information sheets are available free of charge on the CBF website. To order by post please add £1.00 per sheet* | | |
| Communication and challenging behaviour | | | |
| Health and challenging behaviour | | | |
| Challenging behaviour – supporting change (functional assessment) | | | |
| The use of medication | | | |
| The use of physical interventions | | | |
| Specialist equipment and safety adaptations | | | |
| Parents' perspectives | | | |
| Planning for the future: introduction | | | |
| Further information for parents | | | |
| Booklist for professionals | | | |
| BASIC INFORMATION PACK | £10.00* | | |
| The following additional information sheets are not contained in the basic information pack but may be downloaded from the CBF website or ordered separately: | | | |
| Getting a statement | £1.00* | | |
| Self-injurious behaviour | £1.00* | | |
| Pica (eating inedible objects) | £1.00* | | |
| Psychiatric disorders in people with learning disability | £1.00* | | |
| Getting legal authority to make decisions about money, property & welfare | £1.00* | | |
| Difficult sexual behaviour amongst men and boys with learning disabilities | £1.00* | | |
| List of specialist 52-week schools and colleges | £1.00* | | |
| SUB TOTAL CARRIED FORWARD | | | |

*Free to parents/unpaid carers. Registered charities: DVDs £16.50 (or £33.00 for 2-disc set). Prices include postage & packing in the UK only.

/ Continued overleaf...

| SUB TOTAL CARRIED FORWARD | | | |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|--------|---------|
| | Cost | Number | Total £ |
| SUPPORT OPTIONS | | | |
| Planning your House | Web Only** | | |
| Provides family carers with practical help with planning for future housing needs. | | | |
| 8 Ways to get a house | Web Only** | | |
| Explains the different ways to get a house and how they are funded | | | |
| **Due to anticipated changes in funding, these new resources will initially only be available to view on our website www.challengingbehaviour.org.uk . Family carers who would like a printed copy should contact the CBF. Final copies will be available by the end of the year. | | | |
| Planning for the Future: Information Pack England/ Scotland/ N Ireland/ Wales <i>(please specify)</i> | £10.00* | | |
| Contents include: Know your rights; Know the processes; Know your options; Case studies; Understanding the funding; Safeguarding & protecting the individual. With information relevant both for those with children aged 12 and upwards (transition) and those concerned about the support needs of adult sons and daughters. | | | |
| A New Pathway: DVD & report | £10.00* | | |
| This 20 minute DVD provides an overview of a specialist transition service developed to bring four young people back to their local area from out of county residential schools. An accompanying 40-page report reviews how the service was developed. | | | |
| OTHER RESOURCES | | | |
| A guide for advocates (England and Wales) | £16.00* | | |
| Key 'at a glance' bullet points identify 'what you may encounter' and 'what you should know' – a very practical tool for both professional advocates and family carers advocating on behalf of their family member. | | | |
| 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 provide your charity registration number

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

To pay by credit/debit card please telephone us on 01634 838739 (3% card handling fee applies)

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 have no regular guaranteed income.*
- *We do not charge family carers for services or resources.*
- *To keep costs down much of our work is carried out by volunteers.*
- *If everyone reading 'Challenge' gave just £30 a year the guaranteed income would enable us to take forward a number of important projects. (Please ask for details)*
- *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 Foundation

Registered charity number 1060714

Address: The Old Courthouse,
New Road Avenue, Chatham, Kent,
ME4 6BE

Email: info@thecbf.org.uk
Tel. 01634 838739

www.challengingbehaviour.org.uk