



Kent Academic Repository

Osgood, Tony (2008) *Challenging Provision*. . pdf newsletter.

Downloaded from

<https://kar.kent.ac.uk/33608/> The University of Kent's Academic Repository KAR

The version of record is available from

<http://www.challengingbehaviour.org.uk/cbf-resources/newsletters.html>

This document version

Publisher pdf

DOI for this version

Licence for this version

UNSPECIFIED

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).

Challenge

Challenging
BEHAVIOUR
foundation



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

Spring 2008

The newsletter of The Challenging Behaviour Foundation

Location, location

Recently we were contacted by a carer who was planning to move the whole family from the South to the North of England because that was the only place with a service she felt would meet her son's needs.

Setting up specialist local support to meet the needs of someone with severely challenging behaviour cannot happen overnight. But under our present system there is no-one tasked with this development responsibility. The default position is to find a residential home somewhere willing to take the individual. And who knows where that may be!



Vivien Cooper

I have recently been attending planning meetings with a family who want their son to receive the specialist support he needs in his own local area. The attitude of various Social Services staff, initially, was that this just simply could not be done: his needs were 'too' challenging; no-one wanted the responsibility (and extra work!). Buying a 'ready made' out of area placement was seen as the obvious course of action. These professionals were aware of government policy – aware of the family's concerns - but just couldn't see how it could be made to happen.

Today, several meetings later, that attitude has started to change. There are some good people out there trying to change things and some exciting opportunities for self directed services

and supports – we need to get together, families and professionals working as partners, and support each other to make things happen.

In this special edition of 'Challenge' we have attempted to present some of the issues, highlight some good practice, and to provide some tools and resources

that will help you plan for the future. Whether you are a parent or a professional, whether you want extra

***we need to get together,
families and professionals
working as partners***

support at home so that your son/daughter can continue to live with you, or whether you would like to see your son/daughter supported to live as independently as possible in the local community – together we can help turn policy into reality: ie. to develop specialist local support tailored to individual need for individuals who challenge – whatever their age and whatever their location.

• Vivien Cooper

*Chair of Trustees and Founder of the
Challenging Behaviour Foundation*

PAGE 4

A Long and Winding Road

It would have been better for everyone if they had listened to his carer

PAGE 6

Planning for the Future

Probably the biggest decision you will need to make is whether a registered care home or Supported Living would be the best option.

PAGE 7

Resources

With help from the Big Lottery fund, Autism Cymru, Autism N Ireland and PAMIS, Dundee, we now have three new information packs on planning for the future for families living in Wales, Scotland and N Ireland.

PAGE 9

Strength through Partnership

One of the biggest challenges I find as a commissioner is changing how we commission while the money is tied up in a system that is not delivering what the people in it want or need.

'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



Supported by
The National Lottery[®]
through the Big Lottery Fund



Challenging provision

People with the label of challenging behaviour often face a lack of quality local provision.

Individuals described as having challenging behaviour often end up a long way from home because there aren't good local options. About 30% of people supported financially by local authorities in England find themselves 'out of area.'

Quality provision costs money wherever it is located in the UK - it's expensive. But amazingly, poor provision can also cost. Value for money is important, but so is value for quality. High cost provision is not the same as high quality. There are examples of high cost low quality provision. Value for money doesn't mean lowest bidder, and it doesn't follow that spending a lot results in a quality of life.

Rather than spend money in supporting people away from home, perhaps money could be spent in local economies and in developing local quality options. If we don't grow local quality options, then maybe more demand for distant solutions will lead to larger services farther away.

Commissioners have an obligation to help grow local quality options.

We should consider the long-term benefits of developing local expertise and a range of options: small group provision perhaps, supported living, unique family solutions, outreach support, individual budgets, etc. Spending locally can help develop quality options, partnerships, and keep people close to home.

Families and people using provision need to tell commissioners what they want. Loudly.

If 'community care' means anything, surely it means our communities today. It means the development of skills, abilities and capacities. If not here, then where?

Families and people using provision need to tell commissioners what they want. Loudly. Then commissioners can get it organised in partnership with families and providers.

In the past commissioners could offer only what was already there: development of new unique solutions wasn't an option. And commissioners didn't place too many onerous demands on services – they were just grateful they could support the person!

But if commissioners don't explicitly tell Services what they want them to do how can they tell if things are working? If you ask a friend to go into Marks & Spencer with £400 to pick you up a little something for the weekend you really can't have a go when they come back with a gooseberry yoghurt and a fetching 'Per Una' underwear set in the wrong colour when you were really expecting a suit.

Regulation and oversight do not automatically lead to quality, merely compliance to generic standards. Why? Because standards are focused on 'does the service' or 'do they not' meet generic standards, not on outcomes for people, not on the person's desired outcomes, not on aspirations.

One way of identifying quality provision may be to see if people do well - do they develop new skills and do the people around the focal person develop skills and understanding? A good service enables a quality of life: experiences, capacities and skills.

Our challenge now is to engage with commissioners and encourage innovation and the application of what we know about what works and what doesn't. Let's join in advocating for more local quality options for families.

And the best way of advocating is to demonstrate just how good your idea can be in practice. So whether it's in the Garden of England or the Vale of Glamorgan let's wave the pom-poms wildly and start cheerleading for what works.

• **Tony Osgood**

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



FOR ACTION

DOs and DON'Ts for Commissioners

A way forward for commissioners may be to consider these things:

DO	DON'T
<ul style="list-style-type: none"> • Pay for the delivery of what the person desires, based on independent person centred planning 	<ul style="list-style-type: none"> • Pay just for beds or placements
<ul style="list-style-type: none"> • Measure the things that will show if it's working for the person - try growing skills or friends or even – shock - happiness? 	<ul style="list-style-type: none"> • Measure just budgetary savings or protocols or policies
<ul style="list-style-type: none"> • Make sure you can rely on your measurement 	<ul style="list-style-type: none"> • Take the service's word for it
<ul style="list-style-type: none"> • Care about the quality of support 	<ul style="list-style-type: none"> • Care only about the hours of support paid for
<ul style="list-style-type: none"> • Be proactive 	<ul style="list-style-type: none"> • Wait for the crisis

This issue of 'Challenge' is focussing on the development of specialist local support tailored to individual need, however we know that for some families a residential placement may be the best or only available option. Here are the views and experiences of some family carers...

Q: Our son has been at his current school for four years but now his needs have changed and we are thinking about a 52 week placement. What are the experiences of other parents in getting funding for this?

A1: My youngest son who is now 19 has been in residential private schooling for ten years. We had to go to tribunal, but two weeks before our hearing our local authority gave in and gave us the placement.

A2: You have to put down in writing that his needs are not being properly met listing all the provision the present school is not or cannot provide. My son has been in residential since he was nine years old and from being isolated and too challenging to participate in community life is now accessing all kinds of activities

Q: We are just at the end of ten years residential schooling for our son and the nearest adult placement is again a three hour drive away. We continue to look as my husband is now 70 and we cannot continue this drive. Where do we start?

A1: I fully empathise with your situation. I do believe that no place is perfect or ideal in any way, and to a certain extent we have to compromise at various points. The crucial aspect in any home is the care staff who work hands on, and not the management whom you meet at those crucial early stages...

because he has the right help. From my son being excluded constantly he is now living a much happier life.

A3: Just want to say, please think of residential school as a last resort. Once your child goes to residential school you have lost them and they will become institutionalised, probably all their lives. I know other families who have tried foster parents via social services...

A4: I got the teachers and the school's Educational Psychologist to agree that my son's needs had changed. When the Educational panel met, all the reports said that he needed to be somewhere which could cope with his behaviour and improve it, not simply manage it, and they agreed to my request. 52-week boarding has been a godsend for us, I thoroughly recommend it.

From the CBF: Education (including Further Education) is such an important issue we are planning to devote a future issue of 'Challenge' to this topic. Do get in touch if you would like to share your experiences with us.

A2: We also share these experiences and have found a lovely place for our son which is well managed and all of his needs are being met. We wish you all the best in your endeavours to find a suitable placement for your child's transition into adult life...

A3: Ask to see CSCI reports and a "Statement of purpose" when you go to look round any care home. Alternatively, you can ask your social worker to arrange for your son to have his own house (or share) which can be adapted for his specific needs, with his own team of carers - then he would be near you...

From the CBF: Our view is that families should not be in this situation! Families should be properly supported to enable their sons/daughters to live locally with support and services designed around their needs.

What parents say



Tobias & Roz Erskine-Gray

My son, Tobias, was diagnosed as autistic when he was three. Tobias always appeared 'bright' in problem solving but is unable to effectively communicate using verbal communication, and so uses challenging behaviour as a way of saying he is unhappy/ frustrated.

I feel strongly that children and adults who challenge should have the opportunity to enjoy themselves and participate in lots of activities. Now 19, Tobias enjoys a range of activities including walking – even though we as carers find it exhausting, walking as if we are on an army route march!



Tobias camping in the Isle of Wight

Last year we took him to the Isle of Wight. He really enjoyed camping, and we hope to do it again next year.

• Roz Erskine-Gray

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

Flexibility, choice and control

The Vale of Glamorgan Council is committed to promoting and increasing the take-up of Direct Payments across all social work groups, including within the Children with Disabilities Team. In the past two years, the take-up within this team has grown faster than any other, with both parents and case managers seeing the dramatic benefits it can have on the child, their parents and other members of the family. Sol Jörgensen's story highlights the change that Direct Payments can bring, allowing people to live the family life they want whilst ensuring that their child gets the support they need from regular carers that they know and trust.

Receiving Direct Payments means that the family is in charge of when, where, how and by whom the support is provided. This gives flexibility, choice and control which are not always available with other services, but which are so important as it means that the support is tailor-made to suit the child and their needs.

Whilst receiving Direct Payments does involve taking on additional responsibilities, many people have found that the rewards it brings more than outweigh the responsibilities, and at the Vale of Glamorgan we continue to offer our Direct Payments service users ongoing support to assist them with managing their payments. Many people choose to use their Direct Payments to become an employer, however this is not the only way that they can be used and it is important that families understand the different ways in which Direct Payments could benefit them. I hope that Sol's case will encourage more parents and families to look at Direct Payments as a viable option for them and wish Seth and his mother all the best for the future.

• **Lizzie Hale**, *Direct Payments Development Officer, Vale of Glamorgan Social Services*

A long and winding road

Let me introduce you to my small family. I am a single parent with a six-foot sixteen year-old son with severe learning disabilities and severe hypotonia. I've been told that adds up to "complex needs" which is another way of saying that nothing with my son or our life is ever straightforward.

Seth, my son, is unable to speak much, so he is dependent on others to interpret his speech. Carers must have specialised knowledge, including Makaton and computing skills.

Seth has shown challenging behaviour at times, for different lengths of time, and for different reasons. He was written up for psych reports at 12, when he stood up in his wheelchair and pushed the whole thing backwards – straight into the carer whom he loved dearly. She was thrown back against the wall and radiator and cracked her coccyx. He did not realise what pain he had caused – but then again he shows little response to the daily pain he himself is in. He had wanted to leave the table and room because his condition makes sitting uncomfortable and extremely exhausting. He did this because she had been told to keep him

Seth Jörgensen aged nine



Direct Payments and the ILF are worth all the effort of setting them up. It has given me the ability to manage my son's care in a way that I'd always wanted

at the table when he very much wanted to leave the room. She knew this. And it would have been better for everyone if they had listened to his carer, who knew that he needed to move. Enough said.



Seth & Solveig Jörgensen

© Simon Anstey. Used with permission



© Simon Anstey. Used with permission

We now have a substantial package which helps to support me in keeping my son at home. Looking back, though, I have to say we have achieved this only after years of debate, misunderstanding, downright hostility, bridge building, anxiety, anger and many, many tears. It's funny how really everyone does want the same thing in the end – a better life for Seth – but how difficult it can be to agree and then achieve that end.

really everyone does want the same thing in the end – a better life for Seth

So you can only imagine the relief I have felt this year when I suddenly have not one but two workers, who together work Seth's care package. I'm writing this because it is so often the case that things go wrong, or there are more problems in a week than can be counted on two hands, as every parent of a child with disabilities knows. I want to say that Direct Payments and the ILF are worth all the effort of setting them up. It has given me the ability to manage my son's care in a way that I'd always wanted.

My son now presents totally different behaviours than three years ago. He is now a much more independent and confident young man and has a quality of life that other people take for granted but for us feels like freedom. Given the right people, my son is the best that he can be. But, isn't that the same for any child?

• Solveig Jörgensen

Solveig is happy to talk to other parents wishing to set up direct payments. (contact details available through the Challenging Behaviour Foundation office)

So... psych reports followed profiles for home and school. And I can only say that they have proved useful, as I can hand them to people to read before we start discussing new environments, people or any change in routine. I was able to contribute a lot to them, as was his carer. They get updated every two years as his needs and behaviour change. And they proved invaluable when being assessed for Independent Living Fund (ILF), as, together with the care plan, they show my son's complexity in detail. In lurid detail.

Seth has 40 different professionals working on his behalf and a lot of information is in my head. Seth's consultant, Dr Paul Davis, has always been exceptional. I was always here and, as we all know, case managers come and go and then everything has to be explained again. Boring! As if we didn't have enough to do each day or each week just doing our best to care for our loved ones. I can't blame them for moving, though. I wouldn't like to deal with their caseloads either! Before this lot leave, though, I just wanted to say thank you for the energetic and innovative support given to Seth and me by the Vale of Glamorgan Social Services.

Co-ordinating Care

Seth Jörgensen's is a great example of a co-ordinated care package that meets a child's identified needs. Seth has a complex care plan (21 pages long in fact) that details the rehabilitation care that Seth requires on a day-to-day basis. Sol and myself review the care plans on a regular basis to ensure that they continue to meet Seth's needs. We also try to ensure that one of the personal assistants is present when reviewing Seth's care.

Sol and Seth have been lucky enough to find two personal assistants who are both hard working, reliable and clearly passionate about supporting Seth to achieve his full potential by following the guidelines in Seth's care plan and working closely with Seth's mother, Sol.

Sol is the key person in Seth's life. She is proactive, with a determined nature, ensuring that Seth has everything he needs to meet his full potential and to be happy in life. Meeting on a regular basis with Sol is a key factor to ensuring that the care package is running well and Sol is receiving the support she needs to ensure that Seth's needs are met.

I became involved with Sol and Seth when I took over as case manager a year and a half ago. It can be a busy and demanding job, but very rewarding - especially when a care package works so well for a family and you can see the positive effects it has on a child/young person and their family.

• **Rebecca Ashman**, Community Nurse, Children with Disability Team, Vale of Glamorgan

"Sol Jörgensen's story demonstrates the benefits that a direct payments arrangement can bring and I am delighted that it has worked so well for the Jörgensen family. We continue to encourage people to consider taking up the direct payments option and join the 1,600 people in Wales already benefiting from this arrangement."

• **Edwina Hart**, Minister for Health & Social Services, Welsh Assembly Government

It's never too soon to start!

Whatever the age of your son and daughter, there is one thing we would say to all parents: it's never too soon to start planning!

As you think about the future, think about what an 'ideal' scenario for your son/daughter would be. And think creatively - don't accept that you can only choose from what is currently available. Most importantly, start equipping yourself so that you know the key 'tools' that can be used to ensure that your son/daughter receives the individualised support they need.

One such tool for improving the lives of people with learning disabilities is a Person Centred Plan. Person-centred planning means starting with

the individual and putting the supports around them that will enable them to have the life that they want. You may still encounter people who take the (perhaps easier) 'fit the person into what's available' approach, but this should be challenged.

don't accept that you can only choose from what is currently available

For example, if a child/young person has been identified as displaying challenging behaviour, it is likely that he/she will have difficulty accessing many local community services without significant support and/ adaptations to the service. Many local authorities have traditionally

responded to this by purchasing 'out of area' specialist places. These are places that may be able to meet the individual's needs but could be a long way from the family home.

I know from personal experience the huge impact this has on a family – my son spent ten years at a specialist residential school 270 miles away from home. Sometimes this is the only option and you shouldn't feel guilty when this is the case. But if you find yourself in this situation do start insisting early on that steps are taken to plan for your son/daughter's eventual return to your local area. Research has shown that children placed out of area are more likely to move to adult services out of area. Your son/daughter may be

ACCOMMODATION OPTIONS

Registered Care Home or Supported Living?

When considering the 'ideal' scenario for your son or daughter's future, probably the biggest decision you will need to make is whether a registered care home or Supported Living would be the best option.

Until fairly recently, a residential care home was virtually the only option available to people with severe learning disabilities and challenging behaviour apart from living with their families. A common approach was for the local authority to search for an existing residential home that had a vacancy and was willing to take the individual. This culture of 'fitting the person into what is available' has gradually been changing – but we know of commissioners who still adopt this approach, and of many families who still think this is the only option available to them. However, there are now many opportunities for individualised services and support, including self-directed services and the use of direct payments, indirect payments and individualised budgets.

There are of course advantages in

providing a complete, 'all in one' package – not least the fact that the service is usually already up and running and can be viewed. Forward thinking residential care home providers are now much more flexible and person-centred than they were in the past. But while a residential care placement provides a 'complete' service, incorporating

Supported Living means that an individual's accommodation is separate from their care support, meaning that the person cannot be moved against their will. If difficulties arise they may change their care provider but remain secure in their home.

accommodation and care support, families should be aware of the disadvantages of this type of service, particularly for individuals who may display challenging behaviour: if

difficulties arise at any time, the service provider can terminate the contract and the person has to move out.

In contrast, Supported Living is an individualised approach that enables people to choose where they live, how they live, who with, and who supports them. Supported Living means that an individual's accommodation is separate from their care support, meaning that the person cannot be moved against their will. If difficulties arise they may change their care provider but remain secure in their home.

Of course a support package like this can take a great deal of time and effort to set up, and it can be quite hard to get to grips (or even find out about) all the possible funding streams and mechanisms available for this kind of package. Unfortunately in many areas, despite government policy to the contrary, much of the responsibility can end up (at the present time of writing at least) falling to families. But for those who persevere, the benefit to the individual (and to the family) can be immeasurable.

well supported out of area – but he/she could also be well supported locally.

If you are not familiar with person-centred planning (PCP) do take time to find out more as this approach is key to your son or daughter's needs being met. However, it should be noted that a PCP has no statutory power – it is considered best practice, but is not enforceable. It is essential therefore that alongside the PCP, the key requirements are incorporated into the Community Care Assessment Care Plan, which is enforceable in law.

There are now many opportunities for people with severe learning disabilities and challenging behaviour to be well-

think about what an 'ideal' scenario for your son/daughter would be

supported and have a good quality of life within their local community via a person-centred approach. Your local authority should be adopting this approach and should be prepared to develop an individualised local support package to meet your son/daughter's needs. Contact the Challenging Behaviour Foundation for support and information if you find this is not the case.

• **Vivien Cooper**, *Parent Carer*

Founder and Chair of Trustees, the Challenging Behaviour Foundation

NEW RESOURCES FROM THE CBF

Resources for Wales, Scotland, England & N Ireland

With help from the Big Lottery fund, Autism Cymru, Autism N Ireland and PAMIS, Scotland, we now have three new information packs on planning for the future for families living in Wales, Scotland and N Ireland – with a Welsh language version also coming soon.

The new 'Planning for the Future' information packs contain much of the information contained in our Transition information pack (England) and Adult Options (England) information pack, but with references to legislation and contacts for further information now updated to give country specific information.

The packs have been written specifically for families caring for children or adults with severe learning

disabilities described as having challenging behaviour. **Resources are free to family carers.** Please use the order form on page 11.

This special 12-page issue of 'Challenge' has also been funded by the Big Lottery through the National Lottery scheme. If you would like more copies to pass on to friends or colleagues please use the order form on page 11. (while stocks last)

Please note: we are aiming to make all the information in this newsletter and in the information packs available free of charge to both families and professionals through our website www.challengingbehaviour.org.uk by the end of March 2008.

Questions to ask

If you are considering a support provider for your son/daughter, there are a number of questions to ask that can help you decide if they are suitable....

Person centred approach

- Can you provide an example of how you have changed your practice to meet the needs of an individual?
- What adaptations will you make to accommodate my son/daughter's needs?
- How will you support my son/daughter to express his/her individual personality/identity?

Activities and choices

- What will a typical weekday/weekend be like for my son/daughter?
- If a group activity is arranged that my son/daughter does not wish to participate in, what will you do?
- What sorts of choices will be offered? (ranges from breakfast cereal to activities and everything in between!)
- Will my son/daughter be able to choose his/her staff support?

Family

- How do you support families to be actively involved in their sons/daughter's lives?
- Can you put me in touch with other families of people you support?
- Can I visit/contact my son/daughter at any time? Can I visit without an appointment?

Behavioural Management

- What induction, training and ongoing support do your staff receive?
- Do you use a positive behavioural support approach? (recommended by the Royal College of Psychiatry and the British Institute of Learning Disabilities)

Extract from our new 'Planning for the Future' introductory information sheet. To order please see page 11.



Supported by

The National Lottery[®]
through the Big Lottery Fund



Just do it!

Person Centred Planning

"As a priority, councils should fund the independent advocacy and co-ordination required to ensure at least that every person whose behaviour presents serious challenges to services has a proper person-centred plan for the services they need now and in the coming years. Planning ahead also implies building in some capacity in the system to cope with demand as it emerges, rather than waiting until crises occur."

- **ACTION: Does the person you support have a person-centred plan?**

Training

"All services will need staff who have enough understanding of the causes of challenging behaviour to prevent it arising or getting worse. This means that they are trained in person-centred approaches, including person-centred active support, positive behaviour support, total communication approaches, recognising and responding to mental health problems, person-centred planning"

- **ACTION: Have you received the training you need to understand, prevent or reduce challenging behaviour, through a person-centred approach?**

Education, work and day opportunities

"People whose behaviour challenges have the same right to continued education as anyone else. Supported access to further education is an important opportunity which should be available to everyone, alongside supported employment and other day opportunities."

- **ACTION: Does the person you support have access to Further Education, meaningful activities and employment opportunities?**

In 1993 the first version of 'The Mansell Report' was published. This report made wide-ranging recommendations for improved support and services for people with challenging needs in England. The new guidance ('Services for people with learning disabilities and challenging behaviour or mental health needs, revised edition') was published in October 2007 and restates many of Professor Mansell's original recommendations.



Professor Jim Mansell

Here we highlight some of the guidance in the revised report, and suggest action points that you can raise with your local authority.

Service models

"Direct payments and individual budgets provide important new opportunities to provide housing and support in a way that is tailored to the individual needs of the person whose behaviour presents a challenge."

- **ACTION: Have you (or the families known to you) been offered direct payments or an individualised budget (and the support needed to manage these)?**

Value for money

"commissioners should take account of the hidden costs of failure to develop local services, such as the costs of handling crises and placement breakdowns. They should also pay attention to the financial and other costs borne by carers and should avoid increasing the burden on carers by reducing the levels of service."

- **ACTION: Have you (or the families known to you) been reimbursed for any additional costs incurred as a result of caring for a person with challenging behaviour?**

Supporting Families

"People with learning disabilities who have challenging behaviour living at home with their families need two main kinds of service at home: practical support and short breaks to give the person and their family time away from each other."

- **ACTION: Are you (or the families known to you) receiving practical support and/or adequate short breaks?**

Let's do it!

"We know what needs to be done; we just need to do it." Professor Jim Mansell

- **ACTION: If you are experiencing difficulty in any of these areas do let us know. While we do not have the capacity to generate individual solutions we can provide general support and information and will collate the information we receive to use as evidence in our ongoing work to promote better services and support. It's real stories and experiences that we need to campaign for change.**

COMMISSIONERS' CORNER

Thank you to all commissioners who responded to our recent questionnaire. There is clearly some good work taking place around the country. Results of the survey are still being analysed but a number of themes are emerging and the CBF will use this information to take forward our work promoting local individualised support packages.

The majority of commissioners who responded indicated that they would welcome additional support around commissioning for challenging individuals. If you would find it useful to form a Commissioner's email network where successes can be shared or issues can be raised anonymously, please contact us and we would be happy to facilitate this. Email: admin@theCBF.org.uk

Strength through partnership

One of the biggest challenges I find as a commissioner is changing how we commission while the money is tied up in a system that is not delivering what the people in it want or need.

How can we overcome this?

In my experience it is by taking the step into partnership: Partnerships to understand what is needed. Partnerships to initiate innovations. Partnerships to develop good supports. And Partnerships to unlock the money.

In 2002 I was approached by the 'Valuing Medway People' Learning Disability Partnership Board to develop a local Challenging Behaviour Further Education Service for young Medway people living miles away in specialist schools.

A group of interested parties (including the carer-led Challenging Behaviour Foundation) was formalised as a sub group of the Partnership Board. This has been and remains one of the biggest keys to the success of the resulting service. The support of the Partnership Board has enabled the group to progress innovative ideas, sometimes at risk, to enable the young people to return close to home. It has ensured that all decisions meet strategic requirements locally and for the resulting service to shine as an example of national good practice.

An analysis of what it would cost if we continued in the same way and what the costs would be by doing things differently showed that although the cost per person in each model was similar, the qualitative benefits of being innovative and enabling the young people to live in their community were outstanding for all concerned.

It was agreed that the young people would have individual budgets so they could move on at their own pace in both education and care, and so that as the children moved into adult services the money that would have been spent on traditional residential care was invested in the individuals.

The process was challenging and many hurdles had to be overcome to be able to deliver support to the individuals. Membership of the group increased,

and the group evolved into a multi-agency management board (comprising family carers, the University of Kent Tizard Centre, the local college, Learning and Skills Council, Connexions, Health and Social Care), responsible to deliver a service that provided individual supports to people with severe learning disabilities and severely challenging behaviours.

Many questions had to be answered on the way, including registered care versus supported living, discussions with the Commission for Social Care Inspection, training for education and support providers... But one by one with the collective knowledge of management board members we were



Jo Poynter

able to answer and resolve each issue.

With a commitment to best practice and a clear belief that if we can provide quality local services to the most challenging we can do the same for all, this group of partners has been able to influence strategic direction of services in Medway.

So the way forward, I believe, is to develop successful partnerships. It is important to know what we can do as commissioners – but most important is to recognise the strengths of the people around us.

• **Jo Poynter**

Joint Service and Commissioning Manager for Adults with a Learning Disability, Medway



The Medway Challenging Behaviour Further Education Service provides accommodation, 24-hour support, and access to the local mainstream Further Education college, for four young people with severe learning disabilities and severely challenging behaviour, all previously placed out of area in 52-week residential placements. The service is a transition service, preparing the young people for adult life back in their local community.

Two CBF resources tell the story of the development of this innovative new service: a 15 minute DVD highlights the key features and a 40-page report is also available for those interested in using this model to develop specialist local services in their area. (To order see page 11)

Planning to bring people back home

The Special Projects Team in Bro Morgannwg NHS Trust conducted a major epidemiological survey to identify all people with intellectual disabilities and challenging behaviour in their 1.2 million total population region.

Over 100 people in out of area placements were identified, many living far away from their families and friends, and many in very expensive and restrictive environments. These findings led to a major reconsideration of the capacity of local services to provide high quality support to this vulnerable group of people, through joint partnership working between seven unitary authorities and local health boards. Following on from this, work was also undertaken to provide further information on how a forensic learning disability service could be

developed within the region. This involved extensive liaison with the existing services to establish models of service delivery. This work has directly fed into an All Wales review of forensic service provision, ensuring that the needs of people with intellectual disabilities and mental illnesses are fully recognised.

The epidemiological survey was published last year:

Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K. & James, W. (2007) Challenging Behaviours: Prevalence and Topographies. *Journal of Intellectual Disability Research*, 51 (8), 625 – 636.

The work of the Special Projects Team has been summarised in a 5-year brief report which is available from: The Special Projects Team, Unit 3 Cowbridge Court, 58-62 Cowbridge Road West, Cardiff CF5 5BS, Tel: 02920 569204 or by email from Karen.Barnett@bromor-tr.wales.nhs.uk.

Respite complaint upheld

A family has had their complaint against Torfaen County Borough Council upheld by the public services Ombudsman for Wales. Mr & Mrs Telfer complained that the council had failed to provide a consistent level of respite provision for their son who has autism, learning disabilities and severe challenging behaviour. The Ombudsman recommended that the council apologise, make redress of £2,000 for the additional pressure placed on the family and immediately revisit the carer's assessment.

The investigating officer stated: "the council had been aware of John's (not his real name) complex needs for some years but there was no properly directed proactive approach to recruit and train staff to meet his needs. John's assessed needs should have been met and not just made to fit in with available services which were not suitable".

Thank you

A big THANK YOU to the Motley Crew dragonboat team, seen here in action at Bewl Water, Kent, September 2007, raising money for the Challenging Behaviour Foundation. The team have raised a fantastic £3,000 – well done everyone.

While we cannot mention all our donors by name we would like to say a special thank you at this time to the Rotary Club of the Weald of Kent (£500) and St Matthew's Church, Gillingham (£250).

Recent winners of the Challenging Behaviour Foundation 100+ Club, winning £26.25 each were:

September 2007 – Mr & Mrs Graham, Cramlington

October 2007 - Mr & Mrs Barnes, Horsham

November 2007 – Mrs M Parsons, Maidstone (special £50 prize)

December 2007 – Katie Bergg, Burgess Hill

January 2008 – Mr & Mrs Corner, Gillingham



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**.

Mrs Telfer commented: 'This point has needed to be clarified for a long time and I hope that it might prove useful for other CBF members.' If you would like more details please contact the CBF office.

Has your son/daughter been excluded from respite services in the last two years? The CBF would like to hear your experiences in order to raise awareness of this issue.

Training from Cardiff University

Cardiff University is offering a Postgraduate Certificate in Applied Behaviour Analysis and Challenging Behaviour, suitable for anyone currently working in services supporting people with learning disabilities and/or autism, and challenging behaviour, with at least two years experience or an undergraduate degree. The certificate comprises ten taught 3-day modules at monthly intervals commencing September each year, tutor assessed practically-based written assignments and an assessed reading assignment.

For more information visit <http://www.cardiff.ac.uk/wcld> (see 'Teaching'),

Email: wcldoffice@cf.ac.uk or Telephone 029 2068 7204.

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 £
PLANNING FOR THE FUTURE			
Planning for the Future: Introduction Information sheet	£1.00*		
Planning for the Future Information pack: Scotland / N Ireland / Wales: English language version / Wales: Welsh language version <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*		
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		
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			
The use of medication in the treatment of challenging behaviour			
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.

/ Continued overleaf...

SUB TOTAL CARRIED FORWARD			
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). 40 minutes			
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. 40 minutes			
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. 40 minutes.			
POSTAGE & PACKING All prices include postage. For orders outside the UK please add £7.50 per item (administrative charge)			
DONATION – please consider a donation to support our work. Thank you			
TOTAL			

*Free to parents/unpaid carers. 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.

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 (28p 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:

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

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:	
------------------------------------------------------------------------------------------------------------------------------------	--

Name	<input style="width: 95%;" type="text"/>
Organisation	<input style="width: 95%;" type="text"/>
Address	<input style="width: 95%;" type="text"/>
	<input style="width: 95%;" type="text"/>
	<input style="width: 95%;" type="text"/>
Postcode	<input style="width: 95%;" type="text"/>
Telephone	<input style="width: 95%;" type="text"/>

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

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

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 two 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

Foundation is a company limited by guarantee. Registered in England & Wales No 3307407. Registered as a charity No 1060714

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

Email: info@theCBF.org.uk;
Tel: 01634 838739;

www.challengingbehaviour.org.uk