

DESCRIPTION OF THE PRACTICE

1. Title of the practice

Co-production of a local strategy for people with Challenging Behaviour (England)

2. Organisation responsible for the practice

Gloucestershire Learning Disability Joint Commissioning Partnership / Gloucestershire County Council (GCC)

3. Contact person(s)

Name / E-mail	Agy Pasek, Strategy and Transformation Manager, Gloucestershire Learning Disability Partnership, England Agy.Pasek@gloucestershire.gov.uk
------------------	--

4. Summary of the practice

The Challenging Behaviour* Strategy is a commissioning plan for services to support individuals of all ages and all disabilities with challenging behaviour in Gloucestershire.

**“Challenging behaviour” refers to behaviours that people find challenging and can:*

- *put a person’s safety at risk*
- *disrupt home life*
- *stop a person taking part in ordinary social, educational and leisure activities*
- *affect a person’s development and their ability to learn. (source: [SCIE](#))*

Local evidence shows that outcomes for people with a learning disability and challenging behaviour were often poor. Too often, children and young people followed a trajectory of being excluded from special schools. Family members experienced considerable stress and difficulty, while the individual was sent to a residential out of area school. The transition back to the community was difficult, with placement breakdown (i.e. frequent moves), and ultimately the placement of the individual in an inpatient assessment and treatment unit (i.e. residential care). This often led to the medicalisation of the persons’ issues, a ‘label’ about them being very complex and challenging, extremely high cost care packages and limited outcomes in terms of community inclusion.

The Clinical Commissioning Group* and the County Council worked together with families and service users to coproduce, pilot and then implement a solution to try to prevent this trend.

The strategy (and its now commissioned components) cover the whole of the county.

The main lessons learned are:

- Co-production brings better results
- People who use services are the experts
- Successful co-production is less about skills and expertise (professionalising participation and making an industry out of ‘stakeholder engagement’ or producing accessible documents is a waste of time), and more about the values and ethos of the people driving the agenda.

Clinical Commissioning Groups (CCGs) are responsible for the planning and commissioning of **health care services for their local area. There are now 209 CCGs in England.*

5. National/regional/local context of the practice

There is guidance and policy (but no law) which supports service user involvement. It is not financially incentivised in any way, but it is recognised as best practice.

- There is a national programme called '**Transforming Care**' which requires local authorities and CCGs to make detailed plans about their plans to reduce the numbers of inpatient services they use. Local plans are scrutinised and reported on to NHS [National Health Services] England. Using coproduction with people with learning disabilities and their carers is an essential part of these.
- '**Putting People First**' (the national personalisation programme to transform social care) had a strong ethos of moving people from being passive recipients of care to active contributors on an equal footing in terms of power and decision-making.
- Scotland has a coproduction network and resources to encourage the approach <http://www.coproductionscotland.org.uk/about/about/>
- A variety of self-assessments are available to gauge progress. For example: <http://www.scie.org.uk/publications/guides/guide51/>

The strategy was commenced by social care and health colleagues in Learning Disability services. The original impetus was the **abuse** exposed by the BBC's Panorama Programme at Winterbourne View, an independent hospital for people with learning disabilities. The government required local areas to put together clear prevention programmes. There was considerable interest about this locally which led to a strong ethos of coproduction from the start.

6. Staff involved

See sections 12 and 13.

7. Target group

Individuals of all ages and all disabilities with challenging behaviour in Gloucestershire

8. Aims of the practice

Improve outcomes for people with a learning disability and challenging behaviour by:

- Preventing their isolation/exclusion from school
- Placement in a special school, inpatient unit, residential settings
- Supporting families to overcome the stress and difficulties

9. Issues for social services

Service Integration/ Cooperation across services	x	Service Planning	x	Contracting	
Technology		Skills development (of the workforce)		Quality of services	
<u>Others: user involvement</u>	x				

ANALYSIS OF THE PRACTICE

10. Status					
Pilot project (ongoing)	x	Project (ongoing)		Implemented practice (restricted areas)	
Pilot project (terminated)		Project (terminated)		Widely spread practice/rolled out	
11. Scope of the practice					
<p><i>Describe the setting of the practice, considering the following criteria:</i></p> <ul style="list-style-type: none"> • <i>Micro level practice:</i> practice that involves individuals at local level • <i>Meso level practice:</i> practice that involves organisations or communities • <i>Macro level practice:</i> practice that involves large population groups 					
Meso level. Clinical Commissioning Group and the County Council.					
12. Leadership and management of the practice					
<p><i>Description of the leadership of the practice, considering the following criteria:</i></p> <ul style="list-style-type: none"> • <i>Collaborative management:</i> shared between large partnerships, often of central, regional and local representation • <i>Organisational management:</i> by one organisation • <i>Professional management:</i> managed by a single person • <i>Shared management:</i> shared with no defined leadership 					
<p>The initiative was led by a Project Manager representing both organisations - the Clinical Commissioning Group and the County Council. They identified a project manager with a background of running innovative and highly value-driven services for people with challenging behaviour. This was important as they needed a leader whose personal motivation to bring people together to make a real difference to this user group was as strong as their ability to draw a grant chart or deliver a project plan.</p> <p>This individual had both a background of managing community-based services for people with challenging behaviour, as well as a strong ethos of working co-productively and the skills to do so on behalf of the council and the Clinical Commissioning Group.</p> <p>Research into good practice in other areas was also carried out and a series of focus groups and events were held with families and providers. The question they asked repeatedly was: what were the current problems and how could they best address them?</p>					
13. Engaging stakeholders in the practice					
<p><i>Description of the engagement of stakeholders, considering the following criteria:</i></p> <ul style="list-style-type: none"> • <i>Individual practice:</i> individuals have sought practice change • <i>Network approach:</i> one or more organisations develop a network • <i>Collaborative approach:</i> large collaboration with relevant stakeholders 					

From the beginning it was evident that the best way to bring about change was in partnership. Often the individual with challenging behaviour had **a myriad of professionals and organisations** around them so a coordinated approach was required. These included health, education, social care, their family, advocates, private sector providers and the voluntary and community sector. Meaningful change requires both leadership and a groundswell of support, so they planned in a way which ensured both.

The project is jointly led by health and social care (Council and Clinical Commissioning Group).

Also strongly engaged are:

- user-led organisations,
- carers organisations,
- education, and
- housing.

14. Involvement of service users and their families

Description of the involvement of service users, considering the following criteria:

- *Team involvement: service users and carers were part of the practice team*
- *Consultative: a consultative body of users was set up for an on-going dialogue and feedback*
- *Involvement in care: person-centred approaches to care/support*

See above.

15. Costs and resources needed for implementation

Description of how the practice is financed, considering the following criteria:

- *Within existing resources: staff time and other resources are provided 'in-house'*
- *Staffing costs: costs for staff investment*
- *Joint/Pooled budgets: two or more agencies pool budgets to fund services*
- *Funded project: external investment*

Our objective from the outset was that **the cost of the strategy should be funded by the return it delivered in savings**. This meant that only initial funding was required. After one year's funding on a 'proof of concept' basis, one year of full implementation was funded. As the strategy affected both the CCG and the council, it was important that funding sources were shared both in terms of joint accountability, senior sign-up and joint benefit.

Different and imaginative sources of funding were used:

- Approximately GBP 600,000 (ca. EUR 712,000) was re-invested from inpatient services and into the Intensive Support Service (a cost neutral approach for the CCG).
- GBP 150,000 (ca. EUR 180,000) of the new commissioning was funded by the Better Care Fund.
- A further GBP 100,000 (ca. EUR 120,000) was funded by the county council.
- GBP 50,000 (ca. EUR 60,000) was invested from money which would otherwise have been spent on increased provider costs.

Other resources needed were: A project manager.

Ensuring political support and senior management sign-up was also essential to maintaining momentum.

16. Evaluation approaches

Description of the evaluation method of the practice, considering the following criteria:

- *Multi-method*: use of both a qualitative and a quantitative approach
- *Single method*: qualitative or quantitative approach
- *Audit*: looks at data sources such as existing medical records, and/or other routinely collected service data.
- *Informal*: refers to in-house service evaluation using locally designed tools and/or collecting opportunistic feedback
- *No evaluation*
- *An evaluation is planned*

- An initial analysis of the experiences of people with learning disabilities and challenging behaviour revealed that an effective strategy could have considerable impact.
- They found that approximately 250 adults with a learning disability and challenging behaviour were known to services in the county.
- They did not know how many children and young people had challenging behaviour, but the numbers of children transitioning into adult services with a 'challenging behaviour banding' were increasing year on year at a rate of approximately fifteen cases a year.
- They identified that the largest expenditure both for health and social care was on packages of care for individuals with challenging behaviour. Health commissioners were paying a unit cost of GBP 750,000 (ca. EUR 890,000) a year for individuals placed in their NHS provider-run Assessment and Treatment Unit. The average CCG-funded care package for individuals with challenging behaviour was approximately GBP 3,500 (ca. EUR 4,150) a week. The average social care funded package for individuals with challenging behaviour was over GBP 2,000 a week (ca. EUR 2,400) - almost three times the cost of the average package of care. The costs for supporting teenagers with learning disabilities in out of area residential schools was in the same unaffordable ballpark.
- Outcomes for people with learning disabilities and challenging behaviour were worse than for other people with learning disabilities. Nobody with challenging behaviour had secured a successful job outcome through the learning disability employment strategy. The numbers of people with their own tenancies were low. Family carers reported high levels of stress and discontentment and the rates of placement breakdown were alarmingly high.
- The programme was independently evaluated over its' first two years of piloting and implementation by the National Development Team for Inclusion. Systematic methodology was applied, using qualitative and quantitative approaches with stakeholders and professionals.

17. Measurable effects of the practice and what it has achieved for...

Service users

Doing with rather than doing to: the value of coproduction

Coproduction has been an essential part of delivering the strategy. Rather than consulting family carers and people with learning disabilities about the county's plans, they have been actively involved in developing the plans from the start.

Family carers came together in a group which influenced all elements of the strategy: from writing the strategy to reviewing the tender specifications, evaluating the submissions and reviewing progress.

The success of this approach in terms of effectively meeting needs and engaging the community was much commended by families and brought clear benefit to commissioners. It led to the development of a 'Coproduction Charter'

	signed by the council, committing to working in this way across disability services.
Formal care givers	n. a.
Informal carers	n. a.
Organisations	<p><i>Austerity with integrity: how this approach both saved money and delivered better outcomes</i></p> <p>This strategy demonstrated the concept of reducing public sector expenditure by delivering good practice rather than implementing a cuts programme. Attributing cost reductions to this particular initiative cannot always be a precise science due to some of the difficulties of attributing causality in a non resource-intensive way. However, they know that in the last year of implementing the challenging behaviour strategy:</p> <ul style="list-style-type: none"> • The costs of care packages of adults with challenging behaviour have reduced by GBP 750,000 (ca. EUR 900,000). This means that for every £1 invested in the initiative, GBP 2.50 of savings are generated. • During the last two years the Clinical Commissioning Group has removed over GBP 2million of joint funding for people with learning disabilities: about 2/3 of whom have challenging behaviour.
All:	<p><i>Delivering Better Outcomes</i></p> <p>In the last year of delivering the strategy:</p> <ul style="list-style-type: none"> • The early intervention service has carried out functional assessments and written behaviour support plans for 146 children, young people and adults • Over 1,000 support workers have been trained in Positive Behaviour Support. • 150 support workers have been trained in Positive Behaviour Management. • The family support project has worked with 200 families. • Inpatient bed numbers in the county have halved from 12 to 6 and are expected to further reduce to 4 for the next financial year. • Three people with challenging behaviour have jobs. • They feel confident that they are in a good position to meet the requirements of the governments' new Transforming Care programme.
<p>18. <u>Anticipated or 'aspirational'</u> effects of the practice and what it has achieved for...</p> <p><i>This category can include outcomes which are not documented, quantified or properly evaluated. They can include such elements as improved knowledge, quality, workforce, etc.</i></p>	
Service users	n. a.
Formal care givers	n. a.

Informal carers	n. a.
Organisations	The success of the work inspired the council to commit to a broader agenda of coproduction (<i>see practice example on the 'Building Better Lives Programme'</i>).
Other	n. a.

19. How the practice has changed the way the service is provided (lessons learned)

They identified a project manager with a background of running innovative and highly value-driven services for people with challenging behaviour. Research into good practice in other areas was also carried out and a series of focus groups and events were held with families and providers.

The question they asked repeatedly was: **what were the current problems and how could they best address them?**

The next step was to write a strategy which addressed these issues with simple solutions. **There was no evidence base to draw upon so they used innovative tendering methods** such as competitive dialogue to invite providers to think innovatively about how they could contribute to change. Not one of their commissioned projects was an 'off the shelf solution'. All of them required the provider to design and deliver something which they had never delivered before. Finally, to cement the concept that this was something which needed to be delivered in partnership **they wrote a concordat which brought together the key principles and aims of the strategy** and asked organisations to 'sign up' to show their commitment. The concordat has now had over sixty signatories.

➤ ***They learned that providers lacked skills to deliver good outcomes***

... So they commissioned their own unique and consistent training programme. Working in conjunction with a leading academic in the field they designed a contractually enforceable training regime that equipped the right people with the right skills. Providers with limited contact with people with challenging behaviour were given access to an online course in understanding challenging behaviour. Providers delivering support to people with challenging behaviour were asked to attend training in Positive Behaviour Support: an approach which looks at why people display behaviours and takes a structured approach to preventing them. A small number of providers who were supporting people requiring occasional physical intervention were required to attend training in Positive Behaviour Management, provided they also completed the Positive Behaviour Support Training. This not only addressed the skills deficit but also stymied the trend of providers finding people 'difficult to manage' and immediately demanding more hours of 1:1 care to address the problem.

➤ ***They heard that families did not have access to the support they needed to stay resilient and manage during tough times***

... So they changed this by investing in support for them. They commissioned training in managing challenging behaviour from a family-led national charity, giving families (who were living with their loved ones) the same skills and expertise as paid support workers. They also set up a support system which allowed families of children, young people and adults with challenging behaviour to be supported by other families who could empathise with their experiences, provide emotional support and give helpful advice. Families very quickly commented on the difference this had made to them.

➤ ***They found that there was not enough support available to people when they started to show challenging behaviours***

... So they invested in an early intervention service. Termed the 'Positive Behaviour Support Service', they commissioned individuals with expertise in the subject to carry out functional assessments of behaviour (which looked for the cause of a behaviour) and to use this learning to put in place behaviour support plans and model their use. In accordance with the most advanced research about when an intervention is the most effective from the Tizard Centre (University of Kent), the team work with individuals as young as two years old to prevent behaviours from emerging. The cost avoidance from this is difficult to measure without carrying out a longitudinal study, but they believe it will be significant in addressing the current pattern of growth.

➤ ***They saw that there was not enough help when things went wrong***

...So they reduced their inpatient services and re-invested the money saved to create an Learning Disability Intensive Support Service. This is a specialist team which prevents admission to inpatient services or placement breakdown by providing intensive support to the individual in their home. With this additional help people were able to continue to live at home even when things felt very difficult.

20. Sustainability of the practice

Description of whether the practice is sustainable, considering the following criteria:

- *Potential for sustainability:* practice was newly started or is on-going/not yet mainstreamed. How could the practice be sustained (in terms of resources)?
- *Organic sustainability:* service users have been empowered to take the practice forward
- *Established:* the project has been operational for several years

The reduction in expenditure on this user group has led ongoing sustainable funding to be provided to this programme.

21. Transferability of the practice

Description of whether the practice has been transferred, considering the following criteria:

- *Transferred:* transfer to other regions, countries, service user groups, etc.
- *Potential for transferability:* there is interest from the outside; elements of the practice have been taken up and used elsewhere; material for transferability (for ex. training material) has been developed

The practice has been shared as national best practice and presented about in a variety of local forums and conferences.

Other areas are now looking at replicating the model when developing their own 'Transforming Care' plans to reduce the capacity of inpatient services.

There is further potential for transferability of approach for children with emotional and behavioural difficulties, adults with **dementia** and people experiencing a **mental health crisis**.

Sources:

http://www.healthwatchgloucestershire.co.uk/News/Gloucestershires_Challenging_Behaviour_Concordat_2.aspx?page=56483

<http://www.local.gov.uk/documents/10180/12137/Area+case+study+Gloucestershire+web.pdf/d407a2f8-2dbb-4575-bf6b-514fefce334a>