Actions following Panorama investigation

Introduction

This initial statement by the Challenging Behaviour - National Strategy Group (CB-NSG) has been produced in response to the Panorama programme screened on 31st May 2011, which showed systematic and pervasive physical and emotional abuse of people with learning disabilities. People with learning disabilities are still subjected to discrimination, abuse and hate crime in our society. Children and adults with learning disabilities whose behaviour is described as challenging are even more vulnerable and disadvantaged, and at higher risk of isolation, exclusion and of being subjected to abusive and restrictive practices.

The CB- NSG has produced a charter (www.thecbf.org.uk/campaigns/Charter) which emphasises the rights of individuals with learning disabilities who are labelled as challenging as well as setting out what needs to be in place.

The CB-NSG completely supports Professor Jim Mansell's assertion that institutional care is not the answer for people with learning disabilities and that with commitment, vision and drive **it is possible to provide support and care to enable people with learning disabilities who are also challenging, to live fulfilling lives integrated within the community**.

A great deal is known about how to provide good support to individuals whose behaviour is described as challenging, to enable them to live fulfilling lives. Unfortunately, recent media coverage has highlighted systemic failure with horrendous consequences for these individuals and their families. This is indefensible, and a failure to put policy and guidance into practice.

Best practice guidance is available which provides clear information on commissioning appropriate services and support: Department of Health guidance (Professor J Mansell, 1993[i] & 2007[ii]) as well as clinical and service guidelines "Challenging behaviour – a unified approach" (RCPsych, BPS, RCSLT, 2007)[iii].

There is no single quick fix solution. What is needed is a commitment to real change that is robustly implemented. Producing more reports or guidance is not necessary or a good use of resources – what is needed is **a range of actions**, to **deliver** best practice.

Below, the CB-NSG has provided a clear list of actions which need to be implemented in order for people with learning disabilities to receive good, local, high quality support and services that meet their needs. We all have a role to play in ensuring that positive change is delivered.

1. Commissioning: The issues

Commissioning competencies need to be improved across health and social care in terms of local service development and appropriate monitoring of outcomes and quality. Commissioners continue to purchase out of area services or place people in large institutions, without appropriate consideration of developing local individualised support.

There are too many services which house large groups of people, which are unable to provide individualised person-centred support and services.

There is a lack of local specialist provision including intensive community support, and there must be a focus on the development of local specialist expertise, with agreed protocols for entry to and discharge from specialist provision if it is required.

Action:

- Implement the recommendations in Mansell 2, Department of Health guidance (2007), particularly recommendation 15. “Councils should strengthen their commissioning to combine expertise about challenging behaviour with the ability to actually develop the services needed. This is required at both strategic and operational levels. At a strategic level, councils should:
    - Garner resources: work with other relevant agencies to identify all current expenditure on learning disabilities, including resources accessed in emergency or crisis, and obtain agreements to pool these resources to work together to improve outcomes for people whose behaviour presents a challenge
    - Audit provision: find out which services are good at supporting people whose behaviour presents a challenge and which are not, and why.
    - Assess need: find out how many people have behaviour which presents a challenge, including
        - Young people approaching transition from school
        - People placed in the area funded by other authorities
        - People living at home not receiving services
        - People placed out of area
    - Develop partnerships: work with provider organisations who are committed to developing good services to support people whose behaviour presents a challenge to agree commissioning and funding arrangements that will achieve value for money while sustaining investment and development in local services
    - Plan services: forecast the amount of new housing, day opportunities and support that will be required in the years ahead; map the staffing and staff training implications of this; and plan how this will be financed”
- Develop a national template of service specifications regarding what makes a good local service for people with behaviour described as challenging. Commissioning should then be informed by this template, and regulators can utilise it to inspect against.
- Pilot programme in which joint health and social care teams are funded to develop local services that would allow them to break their dependence on private &/ or independent

hospitals and other out of area services and support which provide poor outcomes. Pilot programme to inform future joint commissioning to develop local services.

- Pilot programme of family directed support in which family carers who have a relative who lacks capacity to manage an individual budget are empowered to stimulate the development of local, individualised support.

- Health commissioners to ensure there is a localised specialist multi-disciplinary outreach team that can support people in their own home. Support should be available twenty four hours a day, seven days a week.

- Every local authority to develop a clear pathway to access local expertise, with a time limited assessment process and a treatment plan. Within this pathway, if a specialist provision is required, a discharge plan is agreed for appropriate local provision on entry.

- Department of Health, through the NHS Commissioning board or any new arrangements as they emerge, to monitor commissioning practice in this area judging success on the extent to which service specifications are based on the national template, low number of placement breakdowns and out of area placements.

- The NHS Information Centre should reintroduce into the annual RAP collection from Councils with Social Services Responsibilities data on out of area placements of people with learning disabilities. This was dropped a few years ago, and the Care Quality Commission did collect some information on this through their CRILL data, but also stopped this. As a result, there is no way of knowing how many people with learning disabilities are supported out of area, how this varies by Local Authority and whether it is changing.

- The regional Health Self-Assessment Framework (which is in place in England) monitors outcomes including whether a range of local services is available to individuals who challenge services. Utilise this information to ensure progress is being made year on year in the right direction. This is a transparent way in which local people, commissioners and regulators can ensure that progress is being made.

CB-NSG charter point: *Children's and adults' services will construct long term collaborative plans across education, social and health services and jointly develop and commission support and services to meet the needs of children and adults with learning disabilities, their families and carers.*

2. <u>Leadership, Professional Support & Training: The issues</u>

Supporting people with behaviour that challenges is a skilled and complex job. Any Assessment and Treatment Unit or specialist service for people with learning disability must have a whole organisation approach to Positive Behaviour Support training including a senior manager who has a recognised training qualification in Positive Behaviour Support in order to provide effective and appropriate leadership, mentoring and supervision. Care staff are frequently unskilled and on low pay, with poor training and support to deliver skilled support.

Action:

- Develop a delivery plan to ensure widespread implementation of best practice guidance "*Challenging behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*" Royal College of Psychiatrists, British Psychological Society & Royal College of Speech & Language Therapists (2007).

- Make a recognised Positive Behaviour Support qualification for managers a requirement for registration as part of a whole organisation approach to training.

- Ensure mandatory training supported by qualifications for all care staff about value bases when working with people with learning disabilities, positive behaviour support , types of communication, active support and engaging in meaningful activities, Mental Capacity Act and Deprivation of Liberty Safeguards.

CB-NSG charter point: *People will be supported to have a good quality of life by individuals with the right values, attitudes, training and experience.*

3. <u>"Open" services & independent advocacy: The issues</u>

"Open" services: services that are open to families and outside personnel, including local advocacy and health professionals are more open to scrutiny, and less likely to develop closed and unhealthy cultures. Every individual with a learning disability who is in an assessment and treatment service or out of area provision must have the support of a high quality independent advocate or independent visitor who has knowledge of all the issues including Positive Behaviour Support, personalisation, human rights, dignity & respect.

Action:

- Every individual with a learning disability who is in an assessment and treatment unit or out of area provision must have the support of a high quality independent advocate/independent visitor.

- Advocacy could be provided along the lines of the Independent Visitor model used in children's services and be managed and funded by the Care Quality Commission or via Healthwatch.

- The regulator should monitor "external" visitors to a service, e.g. support to encourage and maintain contact with families, advocates, befriending schemes, registration with a local GP etc.

CB-NSG charter point: *People have the same rights as everyone else to a family and social life, relationships, housing, education, employment and leisure.*

4. <u>Regulation and monitoring: The issues</u>

Current arrangements have failed – they are not fit for purpose. Doing more of the same is not an option.

Action:

- Develop specifically trained inspectors for Learning Disability services, including those who have an expertise in challenging behaviour to ensure that they know what evidence based good practice looks like, the range of community based support available and what they should look for e.g. use of functional assessment and behaviour support plans, frequency of physical restraint, seclusion & PRN medication, injuries to people with learning disabilities and staff, concerns and complaints around behaviour management etc.

- The Care Quality Commission (CQC) should build on previous work (Healthcare Commission/Commission for Social Care Inspection/Mental Health Act Commission) on commissioning for complex needs, and utilise the expertise of family carers of people with complex needs and people with learning disabilities as members of inspection teams.

- Inspections of learning disability and autism services should involve, except where inspectors are certain that people can communicate well and speak freely about their situation, a minimum period of observation focused on the quality of support and interactions between staff and the people they support. Observations should be done using an appropriate and established observational tool. CQC already have the Short Observational Framework for Inspections (SOFI), which we believe was being revised to be more applicable to learning disability services. Inspectors need to have sufficient training, not only in completing the tool, but also in how to observe and what they should look for in order to judge the quality of the support provided and in particular whether it is person-centred and in line with good practice. Training is essential to ensure consistency and reliability in inspectors' ratings".

- CQC inspections must include gaining direct information from the service user and/ advocate and also their family carers and inspectors must have appropriate skills in this area.

- CQC should stop registering the wrong model of service and set a limit on the number of people a service can provide for (as in Wales).

- CQC should publish clear guidance on what type of service can be registered (e.g. NOT large, long-stay "autism hospitals" or services with limited access e.g. locked wards with no access to family carers) although, very rarely highly specialist inpatient units might be required in the short term in order to assess acute mental health problems. This should not be seen as long term provision.

- CQC should ensure services are monitored around outcomes delivered for individuals.

- CQC to provide a search facility to enable family carers, advocates etc. to search online for all the inspection reports of each provider & a separate assessment of the provider as a whole.

CB-NSG charter point: *People and their family carers will receive support and services that are timely, safe, of good quality, co-ordinated and seamless. They will be proactively involved in the planning, commissioning and monitoring of support and services including both specialist and general services.*

5. Accountability & quality assurance of provider organisations: The issues

Provider organisations are accountable for delivering the support required and positive outcomes for individuals. Some people with learning disabilities are placed in services which do not meet their needs or deliver good outcomes for them, and are subjected to inappropriate and harmful restrictive practices.

Good providers focus on positive outcomes for individuals and the reduction of restrictive practices. Provider organisations can lead and be monitored on the reduction of restrictive practices.

Action

- The main boards of companies providing health and social care to vulnerable people must have independent non-executive members and be subject to CQC inspection and accreditation. The main board would need to meet "fit person" standards that have been agreed through consultation with users, families and professionals.

- Transparency in respect of margins, levels of borrowing and the identity of members of the main board. This information is actually available in the public domain but so complicated to find that very few people do. There could also be limits on these in the same way as Community Interest Companies have additional responsibilities.

- Services are required to provide evidence of reduction of restrictive practices (e.g. physical restraint, seclusion etc.) as part of the inspection process.

CB-NSG charter point: *Services should seek to reduce the use of physical intervention, seclusion, mechanical restraint and the inappropriate or harmful use of medication with the clear aim of eliminating them for each individual.*

6. Human Rights & Safeguarding: the issues

The abuse shown in the Panorama documentary was a fundamental violation of the rights of any individual to be free from harm, abuse, exploitation, humiliation and degradation. People with learning disabilities, and in particular those who are labelled as challenging, are less able to stand up for themselves and to be listened to when they cry out for help. They are dependent on others for physical and emotional care and support and all too often, their disability and behaviour are used as pejorative and overarching labels to invalidate their fundamental needs, wishes, distress or pain.

Decisions about the individuals care, support and treatment are often taken without applying the Mental Capacity Act e.g. failing to consult families and other who know the individual well.

Action:

- Speed up the placing of Adult Safeguarding on a statutory footing, with requirements for local authorities, the NHS and provider organisations to demonstrate their compliance with quality assurance standards.

- Ensure that those commissioning services require service providers to demonstrate their compliance with the provisions of the Mental Capacity Act 2005.

CB-NSG charter point: *People will be supported to exercise their human rights (which are the same as everyone else's) to be healthy, full and valued members of their community with respect for their culture, ethnic origin, religion, age, gender, sexuality and disability.*

How can you help?

1. Write to your MP and ask them to support these actions to prevent the abuse of adults with learning disabilities and improve their quality of life. You can find details of your MP here: http://findyourmp.parliament.uk/

2. Sign up to the CB-NSG charter to promote the rights of individuals with learning disabilities who are labelled as challenging. The charter and a sign up form can be downloaded from www.challengingbehaviour.org.uk

3. Contact your local learning disability partnership board and ask them what action they are taking.

4. Ask your Learning Disability Lead Commissioner in your Primary Care Trust to provide information from the Health Self-Assessment Framework about local services and support for individuals with learning disabilities whose behaviour challenges and out of area placements.

ENDS

The **Challenging Behaviour – National Strategy Group (CB-NSG)** is a key national group to address the needs of children, young people and adults with learning disabilities whose behaviour is perceived as challenging.

Members of the CB-NSG include family carers, representatives from the Department of Health, Royal College of Psychiatrists, British Psychological Society, Royal College of GP's, NHS Trusts, researchers, service providers and a range of practitioners, regulators, commissioners and third sector representatives. The group is action and outcome focused and comes together twice a year to monitor progress, share best practice and develop coordinated action plans.

The CB-NSG is co-ordinated by the **Challenging Behaviour Foundation** (registered charity) which provides information, support and training around challenging behaviour associated with severe learning disabilities as well as influencing policy and practice on behalf of this vulnerable group of individuals and their families.

For more information visit: www.challengingbehaviour.org.uk

[i] Department of Health. Services for people with learning disabilities and challenging behaviour or mental health needs: Report of a project group (Chairman:Prof J L Mansell). London: Her Majesty's Stationary Office, 1993.

[ii] Department of Health. Services for people with learning disabilties and challenging behaviour or mental health needs (revised edition). London: Department of Health, 2007.

[iii] Royal College of Psychiatrists, British Psychological Society & Royal College of Speech & Language Therapy. Challenging behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices. College report CR144, 2007.