A NATIONAL RESPONSE TO THE ABUSE OF PEOPLE WITH LEARNING DISABILITIES

Monday June 20th 2011

Rt Honourable David Cameron M.P.
Prime Minister
10 Downing Street
London
SW1A 2AA

Dear Prime Minister,

We, the undersigned 86 people and organisations, have worked for many years to help people with learning disabilities live their lives as full and equal citizens in our society. We were disturbed and distressed to see the evidence of abuse and service failure that was shown on the recent Panorama programme but believe that it is an almost unavoidable consequence of the continuing use of inappropriate services to support some people with learning disabilities.

A number of us have met to consider what should be done to help ensure that people do not continue to be put at risk of facing such abuse. We are aware of the various actions currently being taken within and outside government – such as the DH review and CQC internal inquiry. We hope to make submissions to those both individually and collectively. However, on their own these will not be enough and a clear programme is needed to achieve change. This note gives a summary of the main actions that we collectively believe are needed, both locally and nationally. We were encouraged to hear that you had shown a personal interest in this issue and we urge those with the power and authority to help prevent further such abuse to take note and implement these actions.

We wish to emphasise five important points:

- Our proposals are based on the evidence of what works in public services – knowledge that has been the basis of the policy of successive governments. Those policies just need to be implemented.

- One element of this is that there is no place for hospitals such as Winterbourne View. Beyond a very small number of beds integrated with other local services for short-term assessment and treatment and a small number of others linked to forensic needs, the provision of learning disability hospitals is wrong. The model does not work and should be made unnecessary by competent local services. The only way forward is a planned and properly supported programme of work to replace existing hospitals with proper individualised, evidence based services and supports that are integrated as far as possible into local communities.

- There is a wide consensus across the learning disability field about how to respond to the issues identified by Panorama. Our proposals are not contentious in the field, having

been endorsed by a very broad range of people and organisations, including representatives of people with learning disabilities and family carers.

- Whilst the organisations that particularly failed in allowing the abuse at Winterbourne View should be held to account for their failures, (the provider, the regulator and the various commissioners), focusing only on them would be a mistake. The underpinning issue is one of the overall service and system design – hence the need for Government to take a lead. Without the type of actions we suggest below, there is a very real risk of similar things happening again, elsewhere.

- Whilst this abuse took place in England, under English policy, similar services exist in the other countries of the UK. We are therefore also copying this letter to the relevant Ministers and officials in Scotland, Wales and Northern Ireland (our signatories come from all four countries).

This note will not provide a detailed analysis of what went wrong. Instead, we simply summarise the key actions we believe need to be taken. More detail on these can be found elsewhere[1].

We call upon Government to take a lead by resourcing and overseeing the delivery of the following actions and changes:

[1] See for example:

- Services for People with Learning Disabilities and Challenging Behaviour and/or Mental Health Needs (revised edition) DH (Chair: Prof. J Mansell). March 2007
- Actions Following Panorama Investigation. Challenging Behaviour National Steering Group. June 2011 and Challenging Behaviour National Strategy Group Charter
- Guide for Commissioners of Services for People with Learning Disabilities who Challenge. NDTi (Greig & Offord). 2010
- Challenging Behaviour: A Unified Approach. *College Report CR144*. Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists. June 2007
- WHO Priority Papers: Protection from harm and abuse. 2010

The Issue	Proposed Action
1. The individuals and families from Winterbourne View have faced serious trauma and been victims of crime	1a. People and their families who have been the victims of poor practice at Winterbourne View (and others who may emerge through whistle-blowing, media interest and inspection) should be offered as a matter of urgency, high quality individual and family support and therapeutic interventions as needed in coming to terms with these abuses. Use should be made of the wealth of experience amongst existing family networks when doing this. 1b. When investigating these and other similar abuses, consideration should be given to whether these crimes were motivated by hostility towards disability, thus ensuring that relevant policy is applied and, where appropriate, an enhanced sentence considered by the court.
2. There is no place for specialist hospitals in the care of people with learning disabilities (outside of serious forensic issues). There is clear evidence that such hospitals provide poor outcomes, often at very high cost, and that there are better, alternative ways of supporting people that have behaviour labelled as 'challenging'. There is a place for a small number of local assessment and treatment beds, integrated with other local community services.	2a. Local commissioners should be prevented from commissioning services in such facilities – thus replicating the existing prevention of them purchasing such services within NHS facilities (long stay hospitals and NHS campuses). This could potentially be through a mechanism similar to NICE guidelines, that requires the purchasing of services where there is evidence of success and value for money. 2b. To help effect this for those people currently within such services, the NHS Commissioning Board (in partnership with local government) should instigate a two-year programme to support this change (see point 3a below). 2c. Require every PCT/GP Commissioning consortium (with local authority partners) to openly report the purchase of placements in learning disability hospitals, to a standard national format and definition, to permit local and national monitoring of progress in moving away from such inappropriate models of care.
3. People are being placed in services such as Winterbourne View because of: (i) a lack of local services with the skills and resources to deliver supports that are known to work and deliver better outcomes, and/or	3a. The NHS Commissioning Board, in partnership with local government, should identify resources for a two year programme to support local commissioners to deliver national policy. This should focus on developing local commissioning capacity to ensure (i) high quality person centred reviews of all people currently placed in such services (ii) achieving a cessation of use of such hospitals (iii) the development of high quality local alternatives to institutional provision, (iv) pro-active planning for other individuals to prevent the risk of service breakdown and out of area placement (v) starting this planning with children and teenagers to maximize preventative

(ii) because local commissioners lack the knowledge and skills on how to commission local, evidence based and individualised services for people who are labelled as 'challenging services'.	action (vi) linkage to the developing personal health budgets agenda. People with learning disabilities and families should be involved in delivering this programme. 3b. Local authorities and NHS partners (including new GP commissioners) should implement the existing policy described in the Mansell report and CQC should establish a specific element within its monitoring procedures to review local authority and NHS progress on this – reporting nationally to Ministers. 3c. An in-depth study should be commissioned to build on the existing evidence about value for money, covering both cost and outcomes of different service models. This should encompass authorities that are successfully commissioning local community-based services for people whose behaviour presents a challenge and those that are utilising private sector hospitals.
4. The regulatory framework is failing to pick up on and reduce the risk of such service failings. When basic human rights are at risk, the approach needs to be less focused on an inspectorial methodology and instead also help support service improvement that promotes human rights, respect and dignity	4a. CQC and Government should work with other stakeholders to redefine and establish more effective multi-component systems for safeguarding quality and ensuring service, professional and personal accountability for good practice that also encourages service improvement. 4b This work should include improving and ensuring the expertise of their inspectors/staff in learning disabilities and also in identifying indicators of possible abuse, so that priority is given to listening to and understanding the experiences of service users and their families – including through their direct involvement. 4c. NHS and local authority commissioners should review their competencies in commissioning for people at risk of inappropriate admissions and the care pathways of individuals and report publicly on this. CQC should ensuring its methodologies include reviewing commissioner as well as provider performance – including verifying and reporting on local commissioner-led quality review systems that include people with learning disabilities and families as full partners.
5. If the voices of people with learning disabilities and their families were heard better, then the risks of such abuse would be greatly reduced	5a. All individuals that are placed away from their home area and/or in a hospital service should have access to skilled, independent advocacy (possibly through the local User Led Organisation), funded by the placing authority and complementing and supporting family involvement. Both the purchaser and provider should be required to demonstrate their inclusiveness of and responsiveness to such advocacy. 5b. The national programme and local action described in 3a should specifically include offering

	good early support to families to raise their awareness of what good support is and help them stay 'in control' – one element being to provide families (including siblings) with a guide to their rights in relation to their family members.
6. While it is important not to invest in ways that prolong the life of these units, there is a need to improve quality and safety in the short-term in order to root out abuse, safeguard residents and improve quality whilst replacement services are developed.	6a. Government, in consultation with others, should establish a simple framework of actions required of learning disability hospital services that can be demonstrated and monitored including: o A dramatic reduction in the use of restraint; o Opening up institutions to scrutiny, not least by families and advocates; o Mechanisms to listen and respond to the experience of disabled people and families; o Partnership working with local NHS and social care professionals including evidence of the integrated care pathways to enable people to return to their home communities at the earliest opportunity; o Demonstrating the content, progress and timeliness of clinical interventions and associated clinical accountability as well as clarifying the place of clinical advocacy; o Ensuring opportunities for 'peer challenge' across services; and o Strategies and action for leadership and staff development. 6b Skills for Health should develop workforce guidance for CQC regulated services that covers learning disability hospitals and nursing care, similar to that issued by Skills for Care around residential and community care services.

We also wish to make three wider comments beyond the immediate issues raised by the Panorama programme:

1. There are great similarities between the abuse recently uncovered and that found in NHS facilities in Cornwall and Merton and Sutton a few years ago. Action was taken then that resulted in significant local and national progress. The learning from that appears to have been forgotten, certainly by CQC and many local commissioners – in part we believe because of the continual reorganisation of public services.

2. Despite Ministerial statements that Valuing People remains the Government's policy about people with a learning disability, we know that many local services are starting to de-prioritise its delivery now that national and regional delivery support has been ended. We believe that this will increase the risk of national policy not being followed and poor quality, out-dated services such as Winterbourne View being commissioned and delivered.

3. Whilst this note is purely about people with a learning disability, we are conscious that many of the issues such as about effective commissioning, regulation and listening to people's voice, are also relevant to others in society. For example, recent reports on the neglect of older people in hospital and the Southern Cross situation emphasise the need to view people as individuals with unique needs and not as commercial commodities. Whilst the lack of specific learning disability expertise is undoubtedly a contributory factor to some of the problems we are addressing here, we would also welcome opportunities to consider these issues on a 'cross-client group' basis.

We hope these ideas help to provide a framework for national and local action in response to the evidence highlighted by Panorama and we would welcome the opportunity for a small group of those supporting this letter to meet with you personally to share both our concerns and our ideas. The many organisations and people that we represent and are connected to will be watching with interest to see if, following this public exposure of abuse, decisive action is taken to change the service systems in ways that will reduce the risk of abuse of people with learning disabilities - whilst also ensuring they are supported to lead full, valued and varied lives as equal members of our society.

Yours sincerely,

(Please note the support for this letter goes beyond those 86 listed below, as we have not added the many additional supporting names/organisations received since Friday morning).

Editors of this letter

Rob Greig CBE	Chief Executive National Development Team for Inclusion, former Government National Director for Learning Disabilities
Cllr. Gavin Harding and Amanda Platts	Co-Chairs National Forum of People with Learning Disabilities
Cally Ward MBE	on behalf of the National Valuing Families Forum
Dame Philippa Russell DBE	Parent
Professor Sheila the Baroness Hollins	Crossbench member of the House of Lords, past President of the Royal College of Psychiatrists and parent

Dr. Roger Banks FRCPsych FRCGP (hon.)	On behalf of the Challenging Behaviour – National Strategy Group
Dr. David Towell	Director, Centre for Inclusive Futures and Trustee, Richmond Mencap
Viv Cooper	Challenging Behaviour Foundation and parent
Keith Smith	Chief Executive, on behalf of the British Institute of Learning Disabilities
Alison Giraud Saunders and Barbara Macintosh	Co-Directors, Foundation for People with Learning Disabilities
Bill Love	Programme Director Learning Disabilities on behalf of the National Development Team for Inclusion (NDTi)
David Congdon	Head of Campaigns, Mencap
Lynn James Jenkinson	Director, North West Training and Development Team and parent
Samantha Clark	Chief Executive on behalf of Inclusion North
Fiona Ritchie OBE	formerly senior policy lead, learning disabilities, Healthcare Commission/CQC
Christine Braithwaite	Director of Policy & External Relations, The Council for Healthcare Regulatory Excellence, former Member of the Cornwall Investigation Team
Yvonne Cox	Chair of Oxfordshire Family Support Network, formally Chief Executive of Ridgeway Partnership NHS Trust.
John Hersov	Independent advocacy facilitator/consultant
Advocacy Organisations	
Michael Ratcliffe	On behalf of Taking Part (Shropshire and Telford and Wrekin)
	Speakup Self-advocacy
Professor Peter Beresford	Chair, Shaping Our Lives
Philipa Bragman	Director, on of behalf of Change
Clare Wightman	Director and on behalf of Grapevine Coventry and Warwickshire
Rick Henderson	Chief Executive, Axtion4Advocacy
Steven Robertson	Chairperson of People First (Scotland)
	Voice4Kent

Family organisations	
	National Family Carer Network
Jean Willson OBE	Chair of Centre 404 and parent
Julia Erskine	On behalf of Merseyside Partners
Lynne Elwell	On behalf of Partners in Policymaking
Jackie Clarke	On behalf of Inclusion South West
Professional and Representative bodies	
Dr Ian Hall	Chair of the Faculty of the Psychiatry of Learning Disability, on behalf of the Royal College of Psychiatrists
Dr. Theresa Joyce	on behalf of the Learning Disability Faculty of the British Psychological Society
Dr. Matt Hoghton	Royal College of GPs, Learning Disability Champion
Liz Sayce OBE	Chief Executive on behalf of RADAR
Jane Livingstone	Acting Chief Executive on behalf of ARC
Kim Foo	Chair and on behalf of the Association for Supported Living
Jim Crowe	On behalf of Learning Disability Wales
Dr Lisa Curtice,	Director, Scottish Consortium for Learning Disability
Academics	
Professor Eric Emerson and Professor Chris Hatton	On behalf of the Centre for Disability Research, Lancaster University
Professor David Felce	Welsh Centre for Learning Disabilities and Past President of the International Association for the Scientific Study of Intellectual Disability
Peter McGill	On behalf of the Tizard Centre, University of Kent
Professor Kelley Johnson	Director, on behalf of the Norah Fry Research Centre, University of Bristol
Professor Roy McConkey	Centre for Intellectual and Developmental Disabilities, University of Ulster,
Professor Ann Davis	Institute for Applied Social Studies, University of Birmingham

Professor Chris Oliver	Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham
Policy and Development Support agencies	
Christine Lenehan	Director, on behalf of the Council for Disabled Children
Stephen Bowen	Director, British Institute of Human Rights
Joanna Perry	Chair on behalf of Values into Action (VIA)
	All members of the original Valuing People Support Team
Julie Stansfield	Chief Executive on behalf of In Control
Janet Cobb	Manager UK Health and Learning Disability Network
Helen Sanderson	HSA
Sally Warren	Managing Director - Paradigm
Sian Lockwood	Chief Executive Community Catalysts
Mandy Neville	Chief Executive Officer, Circles Network
Gary Fitzgerald	Chief Executive, Action for Elder Abuse
Commissioners and Providers	
Su Sayer OBE	Chief Executive United Response
Liz Bruce	Strategic Director, Adults, Manchester City Council, ADASS NW lead for people with learning disabilities.
Amanda Reynolds	On behalf of South Essex Partnership University NHS foundation Trust
Karyn Kirkpatrick	Chief Executive, Keyring
Professor Mark Burton	Head of Manchester Learning Disability Partnership and Visiting Professor, Manchester Metropolitan University.
Steven Rose	Chief Executive on behalf of Choice Support
Jane Pettingell	Chief Executive Generate (Opportunities Ltd)
Paul Allen	Chief Executive, Redbridge Community Housing Ltd. (RCHL)
Steve Scown	Chief Executive on behalf of Dimensions
Peter Thompson	Chief Executive, mcch society
Dave Barras	Positive Support in Tees CIC

Prof (Dr) Zenobia Nadirshaw	Consultant Psychologist Central London Community Healthcare NHS Trust and University of West London
Lucy Hurst-Brown	Chief Executive on behalf of Brandon Trust
Bill Mumford	Managing Director: MacIntyre
Sean Kelly	Chief Executive, Elfrida Society
John Sargent	L'Arche UK
Other individuals and organisations	
Peter Mittler	UN consultant on disability and education
Dr Oliver Russell	formerly Senior Policy Adviser on Learning Disabilities, Department of Health (1998-2001)
Professor Duncan Mitchell	Editor, British Journal of Learning Disabilities
Elinor Harbridge	Editor Community Living
Andy Bradley	Frameworks 4 Change
Jane Petingell	Generate
Andrew Holman	Inspired Services
Tom McLean	Trustee to various charities
International	
John O'Brien	The Center on Human Policy, Law, and Disability Studies, Syracuse University
Dr. Nan Carle	Director, Initiative for Inclusive Communities, Arizona State University
Phil Madden	Vice President EASPD (European Association of Service Providers for People with Disabilities)
Lyn Rucker	Community and Court Monitor, New Mexico and Massachusetts

Cc Andrew Lansley - Secretary of State for Health
Paul Burstow - Minister of State for the Department of Health
Una O'Brien - Permanent Secretary at the Department of Health
David Behan - Department of Health's Director General of Social Care, Local Government and Care Partnerships
Anne Williams - National Director for Learning Disabilities
Relevant ministers and officials in Scotland, Wales and Northern Ireland

Since sending the letter to the Prime Minister, the following have expressed their support

Baroness Jane Campbell	Crossbench Member of the House of Lords
Baroness Audrey Emerton	Crossbench Member of the House of Lords
Mark Constant	Managing Director, Care Solutions Group
Siobhan Bogues	ARC Northern Ireland
Sue Pemberton	Chief Executive Officer on behalf of Integrate (Preston and Chorley)
	Eastern Region Forum of People with Learning Disabilities
Nick Fripp	Head of Service, Learning Disabilities, Cornwall
Karen Burrow	On behalf of Spire (Preston) Ltd
Paul Snell	Chief Executive on behalf of Walsingham
Rohhss Chapman	School of Education, University of Manchester
Leo Bishop	Formerly Commissioning Manager, Learning Disabilities, Essex County Council
Sue Sharples	Chief Executive, Ormerod Group
Steve James	Group Chief Executive, Avenues
Dr. Vaso Totsika	North Wales Clinical Psychology Programme, Bangor University
Kathleen O'Gorman	Chair, National Board of Trustees for L'Arche UK
David Leadbetter and Brodie Patterson	Directors, CALM Training Ltd
Andy McDonnell	Studio 3
Paul Daly	Shared Approach Ltd
Rosemary Trustam	On behalf of Disability Equality Northwest
David Wolverson	
David Naden	Chairperson, Lancashire Learning Disability Voluntary Sector Providers Consortium
	The Trainers and Researchers at Building Bridges Training
Jo Clare	Chief Executive, Three Cs Support
David Allen	Associate Clinical Director, Abertawe Bro Morgannwg University Health Board

Des Sowerby	
Jo Kidd	Chief Executive, Skillnet Group CIC
Dr. Sandy Toogood	Senior Lecturer in Applied Behaviour Analysis, Bangor University
Professor Cathy Lowe and Dr. Edwin Jones	Special Projects Team, Abertawe Bro Morgannwg University NHS Trust
Jackie Hayes	Service manager on behalf of Quarriers
Nicola Grove	Director, on behalf of Openstorytellers