Chloe Hayward
United Kingdom Acquired Brain Injury Forum
Kemp House
152-160 City Road, London
EC1V 2NX

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Mental Capacity Act Code of Practice: Call for evidence

Acquired Brain Injury and Mental Capacity

We very much welcome the opportunity to inform the discussion around the review of the Mental Capacity Act Code of Practice. We hope that this submission will firstly inform the relevant debate but, secondly, will develop opportunities for further consultation and engagement with individuals, families, professionals and organisations with an interest in Acquired Brain Injury (ABI). The original Code of Practice was a well written and intentioned document, however utilisation in practice has been far more problematic.

As the House of Lords review so clearly demonstrated, in relation to ABI, there are condition specific challenges that are regularly picked up in practice and repeating themes and issues are now more identifiable (House of Lords, 2014). The review of the Code of Practice provides a unique opportunity to address these issues, to frame the problems identified and to support individuals, families and practitioners to work more collegiately, to promote autonomy and protect human rights, to ensure the welfare of individuals is safeguarded and develop resources and ways of working that reduce conflict.

In particular in relation to ABI we would note:

1. A lack of underpinning knowledge of ABI, how it impacts upon functioning, reasoning, decision-making and behaviour is common across many professional groups, including those with responsibilities to assess mental capacity and/or act as Best Interests Assessors. Often training appears to focus upon the Act and not upon the ABI related difficulties that give rise to difficulties with decision-making (Acquired Brain Injury and Mental Capacity Act Interest Group, 2014). This is clearly nonsensical and creates situations whereby professional staff are acting out-with of their expertise and likely in breach of the relevant professional standards.
2. The lack of knowledge of ABI and how it affects functioning particularly (but not exclusively) manifests with a failure to understand executive impairment, especially in the context of reduced insight. Such failures of knowledge and understanding lead to ill-informed assessments or an absence of assessment. This has been noted to lead to death and/or serious harm in the case of ABI (Flynn, 2016, Summerfield, 2011, Norman, 2016).
3. Despite previous guidance, non-ABI-specialist staff are regularly noted to fail to seek the support of specialist colleagues or, in some instances, to actively dismiss or ignore such advice and support (George and Gilbert, 2018).
4. A failure to understand ABI and to utilise the skills of others who do have knowledge and experience of the condition leads to flawed assessment processes which are based upon

verbal output of the assessed person, not their actual functioning in practice. ABI knowledgeable staff recognise the need to triangulate evidence from verbal assessment, observation and third-party information to ensure that assessments are accurate, neither over or under-estimating actual functional ability (Manchester et al., 2004).

5. Lack of knowledge of both ABI and of the neuro-rehabilitative approaches that support individuals to make (and sustain) functional gains over time, reduces an assessor's capacity to conceptualise how decision making can be supported. Statutory principle two of the Act is therefore liable to be ignored or misapplied with all of the concomitant risks of this failure of application (Norman et al., 2018, NICE, 2018).
6. Assessment of individuals with an ABI is complex; individuals are very regularly noted to be "good in theory, poor in practice" with a notable disconnect between what is said and what is done. Full, adequate and accurate assessment is a process that requires specialist knowledge (Owen et al., 2017, Lennard, 2016).
7. Failure to assess adequately, based upon a lack of knowledge, a flawed assessment process and a lack of integration of third-party evidence (family and professional) leaves people with an ABI inadequately supported, irrespective of whether an individual has or does not have capacity regarding a specific decision. In such circumstances it is very regularly family that shoulder the subsequent burden (Headway, 2015).

We believe that the Code of Practice can be bolstered to take account of the difficulties experienced in practice and that the above points are a good starting point in relation to ABI. We look forward to working with a range of interested parties to ensure that the needs of individuals and families affected by ABI are taken account of and responded to.

Yours

Dr Tom Balchin, Director, **The ARNI Institute**

Dr Andrew Bateman, Chair, **United Kingdom Acquired Brain Injury Forum**

Chris Bryant MP, Chair, **All Party Parliamentary Group on Acquired Brain Injury**

Jackie Burt, Chair, **Brain Injury Social Work Group**

Alison Clarke, Practice Board Chair, **British Psychological Society**

Dr Ava Easton, Chief Executive, **The Encephalitis Society**

Joss Gaynor, Head of Foundation, **The Disabilities Trust**

Angela Kerr, Chair, **British Association of Brain Injury Case Managers**

Dalton Leong, **The Children's Trust Tadworth Court**

Raymond Lynch, founder member, **Brain Injury Touchpoint**

Peter McCabe, Chief Executive, **Headway – the brain injury association**

Lesley Pope, Chair, **Independent Neurorehabilitation Providers Alliance**

Professor Grahame Simpson, Chair, **International Social Work and Acquired Brain Injury Group**

Paul Spence, CEO & Founder, **P.A.U.L For Brain Recovery**

Lisa Turan, Chief Executive Officer, **Child Brain Injury Trust**

Sandy Weatherhead, Executive Director, **British Society of Rehabilitation Medicine**

And

Dr Simon Abbott, Senior lecturer in Social Work, **Kingston University & St George's University of London**

Dr Rob Agnew**,** Consultant Clinical Psychologist in Neurorehabilitation, Autism and Challenging Behaviour, **Homerton University Hospital NHS Trust and University College London**

Sheila Aitken, Brain Injury Case Manager, **Head First LLP**

Simon Akroyd, Case Manager, **Mercia Case Management**

Yogi Amin, National Head of Public Law and Human Rights, **Irwin Mitchell LLP**

Leigh Andrews, Director, **ChgCommCIC**

Catherine Atkinson, Consultant Allied Health Professional, **Homerton University Hospital NHS Foundation Trust**

Pat Bardsley, Clinical Case Manager, **Amber Case Management Ltd**

Toby Beck, Case Manager and Expert Witness, **Bush and Co.**

Patrick Boyd, Brain Injury Case Manager & Registered Social Worker, **Care and Case Management Services Ltd.**

Bill Braithwaite QC, **Exchange Chambers**

Suzy Braye, Emerita Professor of Social Work and independent adult safeguarding consultant, **University of Sussex**,

Stuart Brazington, Partner, Head of Brain injury, **Royds Withy King solicitors**

Dr Neil Brooks, Consultant Neuropsychologist, **Rehab Without Walls**

Helena Bryant, Clinical Director, **Brownbill Associates Ltd**

Professor Paul W. Burgess, Institute of Cognitive Neuroscience, **University College London**

Barbara Chambers, Case Manager, **Community Case Management Services Ltd**

Louise Chance, Director, **A Chance for Life Ltd**

Jo Clark Wilson, Director, **Head First Assessment and Case Management LLP**

Nicole Cocksedge, Occupational Therapist Case Manager, **Unite Professionals Ltd**

Ella Cornforth, Expert Lead, **JS Parker Limited**

Kevin Cross, Director, **KCCM ltd**

Sally and David Cullen, **Family member**

Andrew Dart, **Family member and commissioner of services**

Caroline Dart, **Trustee of a Brain Injured person's Trust Fund**

Ellie and Benjamin Dart, **Family members**

Jackie Dean, Clinical Director, **N-Able Services**

Hilary Dicks, Partner, **Creative Case Solutions**

Dr Michael Dilley, Consultant Neuropsychiatrist in Neurorehabilitation**, Brain & Mind Ltd**

Eddie Fardell, Head of the Court of Protection department, **Thomson Snell and Passmore**

Phillippa Feltham-White, Occupational Therapist, **Bush and Co.**

Sally de la Fontaine, Director and physiotherapist, **Milestones Clinic Ltd**

Professor Rachel Fyson, Director of Centre for Social Work, **University of Nottingham**

Dr Melanie George, Consultant Neuropsychologist**, Kent and Medway NHS and Social Care Partnership Trust**

Rosie Gibbons, Case Manager, **Westcountry Case Management**

Dr Sam Gilbert, Associate Professor of Cognitive Neuroscience, **University College London**

Sarah Griggs, Partner, **Irwin Mitchell LLP**

Dorian Harper, Project Manager, **Langstone Society Community Support**

Lisa Harris, Clinical Lead, **P.A.U.L For Brain Recovery**

Sarah Harrison, Regional Manager, **JS Parker Limited**

Tony Hart, Chair, **Acquired Brain Injury Forum for London**

Jane Hogg, Occupational Therapist and Case Manager, **Westcountry Case Management Ltd, care expert with Peritus Network**

Penny Haysom, Brain Injury Case Manager, **Head First LLP**

Sally Hoare, Case Manager, **Westcountry Case Management Ltd**

Dr Mark Holloway, Brain Injury Case Manager and Expert Witness**, Head First LLP**

Susan Holmes, Occupational Therapist and Case Manager, **Tania Brown Ltd**

Fiona Howson, Regional Manager Manchester, **JS Parker Limited**

Dr Howard Jackson, Consultant Clinical Neuropsychologist and Clinical Director, **TRU Ltd**

Cathy Johnson, Clinical Director, **Rehab Without Walls**

Alex Jones, Neuro Occupational Therapist, **Alex Jones Ltd**

Christian Kerr, Consultant Social Worker (mental health), **Gateshead Council**

Dr Mark Linden, Lecturer in Health Sciences, **Queen's University Belfast**

Julia Lomas, National Head of Court of Protection, **Irwin Mitchell LLP**

Dr Richard Maddicks, Consultant Clinical Neuropsychologist and Director, **Psychology Chartered Ltd**

Dr Andy Mantell, Senior Social Work Lecturer, **University of Greenwich**

Glenys Marriott, Chair, **Cumbria Neurological Alliance**

Gerard Martin QC, **Exchange Chambers**

Steve Morgan Dip COT, MA, Case Manager, **Westcountry Case Management Ltd**

Dr Jane McNeil, Consultant Clinical Neuropsychologist, **Solent NHS Trust**

Claire Morris, Case Manager, **Rehab Without Walls**

Debra Mullally, **Family member**

Benjamin Needham-Holmes, Operations Manager, **Bush & Company Rehabilitation**

Leigh North, Business Lead, **P.A.U.L For Brain Recovery**

Dr David Orr, Senior Lecturer in Social Work, **University of Sussex**

Dr Gareth Owen, Reader/Hon Consultant Psychiatrist, Mental Health, Ethics and Law Research Group, **King's College London**

Lucy Naven, Training and Quality Manager, **JS Parker Limited**

Dr Alyson Norman, Clinical Psychology Programme Lead, **University of Plymouth**

Anita Pascoe, Clinical Lead, **Westcountry Case Management**

Laura Pell, Brain Injury Case Manager, **The Rehabilitation Partnership**

Joanne Pendlebury, Brain Injury Case Manager, **Head First LLP**

Janet Penny, Director, **Link Case Management Ltd**

Dawn Perry, Neurological Occupational Therapist, **Tamworth & Lichfield Brain Injury Support Group**

Shelley Prince, Brain Injury Case Manager, **Northern Case Management Ltd**

Denyse Procter, Case Manager, **Westcountry Case Management Ltd**

Maggie Sargent RGN, **Community Case Management Services Limited / Maggie Sargent & Associates**

Stephanie Seymour, Brain Injury Case Manager, **Head First LLP**

Becky Simpson, Specialist Clinical Lead Occupational Therapist, Acquired Brain Injury/Complex Care case manager, **Enable Therapy Services**

Denise Slack, Clinical Lead Rehabilitation, **JS Parker Limited**

Laura Slader, Independent neurological specialist OT, **LSOT Ltd**

Nicola Smith, Director, **Stanley Smith Case Management**

Sue Stoten, Managing Director and Clinical Director for Adult Services, **Anglia Case Management**

Dr Christopher Symeon, Consultant Neuropsychiatrist, **St George's University Hospitals NHS Foundation Trust**

Jo Throp, Clinical Director, **Krysalis Consultancy Ltd**

Emily de Vulder, Brain Injury Case Manager, **Head First LLP**

Gill Walker, Consultant Case Manager and Expert Witness, **Gwcare**

Jane Warren, Clinical Lead Case Management, **JS Parker Limited**

Anna Watkiss, National Clinical Co-ordinator, **Tania Brown Ltd**

Jenny Webster, Case Manager, **Westcountry Case Management Ltd**

Catherine Wignall MSc, Brain Injury Case Manager / Neuro Occupational Therapist**, Independent Living Solutions**

Sally Wilkinson, Clinical Director, **JS Parker Limited**

Christina Wilks, Regional Manager, Children and Young Peoples Services, **JS Parker Limited**

Claire Williams, **Assoc Professor, Department of Psychology, Swansea University**

Professor Huw Williams, A/Professor in Clinical Neuropsychology, **University of Exeter**

Liz Williamson, Speech and Language Therapist, **The Speech Group**

Jacky Winfield, Brain Injury Case Manager, **Head First LLP**

Sonia Woodward, Independent Occupational Therapist and Case Manager, **Sonia Woodward Ltd**

Professor Andrew Worthington, Consultant Clinical Neuropsychologist and Director, **Headwise**

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