

Membership of Learning disabilities and behaviour that challenges: service design and delivery Guideline Committee

The Committee will operate as an advisory Committee to NICE's Board, developing a guideline on Service model for people with learning disabilities and behaviour that challenges.

The terms of reference and standing orders for the Committee can be found in [appendix D of Developing NICE guidelines: the manual](#).

Membership list

Name	Job Title, Organisation
Chair	
Jonathan Senker	Chief Executive, VoiceAbility
Vice-chair	
Jeremy Winter	Team Manager for the Learning Disability and Autism Team, Preston and South Ribble
Core members / Members	
Alex Cookson	Lead Consultant Clinical Psychologist and Lead for Transforming Care, Mersey
Alix Lewer	Founding Director of The Include Choir
Andrea Wiggins	New Project Director, Avenues Group
Isaac Samuels	Expert by Experience
Jane Stroud	Social worker, Learning Disability Services, Somerset County Council
John Devapriam	Consultant Psychiatrist & Clinical Director for Acute, Rehabilitation and Forensic Secure Mental Health Services, Leicestershire Partnership Trust
Karin Fuchs	Consultant Clinical Psychologist, West Sussex Learning Disability Services, Sussex Partnership NHS Trust
Laura Searle	Deputy Head, Avalon Special School, Street, Somerset
Mark Harvey	Head of Social Work & Communities and Principle Social Worker, Hertfordshire County Council
Melanie Bruce	Highly Specialist Clinical Psychologist and Lead, Norfolk Community Health and Care NHS Trust
Naomi Sills	Team Manager, Countywide Transitions
Pam Bebbington	Expert by Experience
Paul Scarrott	Expert by Experience
Rafik Hamaizia	Expert by Experience
Richard Hastings	Professor, Centre for Educational

	Development, Appraisal and Research, University of Warwick
Rowena Tye	Carer
Sharon Jeffreys	Chief Commissioning Manager Mental Health, Learning Disabilities and Autism, South West Lincolnshire Clinical Commissioning Group
Veronique Kaboha	Carer
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation
Topic expert members	
Lisa Hopkins	Chief Executive, SeeAbility

Date last reviewed: 23/03/2018

Declaration of Interests

Name	Job title, organisation	Declarations of Interest, date declared (recruitment / committee meeting)	Type of interest	Decision taken
Alex Cookson	Lead Consultant Clinical Psychologist and Lead for Transforming Care, Mersey.	None		No action needed
Alix Lewer	Founding Director of The Include Choir	Member of the Executive Committee of East Surrey Mencap and recently made an accessible questionnaire for them which aims to gather information about whether cuts to benefits or social care provision are affecting quality of life or increasing risks for of people with learning disabilities (some of whom have behaviour which challenges) (Declared at GC 9 – 09/03/17)	Personal non-financial (specific)	Declared and participated
Andrea Wiggins	New Project Director, Avenues Group	Currently works for a provider who provides congregate and non-congregate settings for people with learning disabilities (GC 4 – 01/06/16)	Non-personal financial (specific)	Declared and participated
Andrea Wiggins	New Project Director, Avenues Group	Co-authored papers included in the review at GC 6 (Declared at GC 6 – 03/10/16)	Personal non-financial (specific)	Declared and did not participate in any discussions or in writing any recommendations related to the specific evidence statement

Gary Bye (Feb 2016 – Sep 2017)	Chief Executive, Life Path Trust Ltd	Trustee and Director of Association for Real Change, a charity supporting providers of services to people with a learning disability (Declared at recruitment)	Non- personal financial (non- specific)	Declared and participated
Isaac Samuels	Expert by experience	People's Committee UEL (Declared at recruitment)	Personal non- financial (non- specific)	Declared and participated
Isaac Samuels	Expert by experience	Member of research group City University (Declared at recruitment)	Personal non- financial (non- specific)	Declared and participated
Isaac Samuels	Expert by experience	Redbridge Rainbow committee member (Declared at recruitment)	Personal non- financial (non- specific)	Declared and participated
Isaac Samuels	Expert by experience	National co-production advisory group member SCI/TLAP (Declared at recruitment)	Personal non- financial (non- specific)	Declared and participated
Isaac Samuels	Expert by experience	Blogger and guest writer Baseline magazine (Declared at recruitment)	Personal non- financial (non- specific)	Declared and participated
Isaac Samuels	Expert by experience	Health watch member (Declared at recruitment)	Personal non- financial (non- specific)	Declared and participated
Isaac Samuels	Expert by experience	Freelance consultant (sexual health, mental ill health, co-production and choice and control, equity diversity) (Declared at recruitment)	Personal non- financial (non- specific)	Declared and participated
Isaac Samuels	Expert by experience	Peoples panel Expo- NHS 2015 (Declared at	Personal non- financial (non-	Declared and participated

		recruitment)	specific)	
Isaac Samuels	Expert by experience	Newham council employment task group member (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	Expert by experience	Newham council coproduction member (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	Expert by experience	LGA -Peer Reviewer (Commission of better outcomes) (Recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	Expert by experience	Part of the IPC Programme Board (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Jane Stroud	Social worker, Learning Disability Services, Somerset County Council	None		No action needed
Jeremy Winter	Team Manager for the Learning Disability and Autism Team, Preston and South Ribble	Author of an article in a book on 'Interprofessional Supervision' (Declared at recruitment)	Personal financial (non-specific)	Declared and participated
John Devapriam	Consultant Psychiatrist & Clinical Director for Acute, Rehabilitation and Forensic Secure Mental Health Services, Leicestershire Partnership Trust	Independent regulator of health and social care services at the Care Quality Commission (Declared at recruitment)	Non-personal financial (non-specific)	Declared and participated
John Devapriam	Consultant Psychiatrist & Clinical Director for Acute, Rehabilitation and	Member of the Quality Network for Disabilities at the Royal College of Physicians.	Personal non-financial (non-specific)	Declared and participated

	Forensic Secure Mental Health Services, Leicestershire Partnership Trust	(Declared at recruitment)		
John Devapriam	Consultant Psychiatrist & Clinical Director for Acute, Rehabilitation and Forensic Secure Mental Health Services, Leicestershire Partnership Trust	Co-authored papers included in review at GC 5 (Declared at GC 5 – 10/08/16)	Personal non-financial (specific)	Declared and did not participate in any discussions or in writing any recommendations related to the specific evidence statement
John Devapriam	Consultant Psychiatrist & Clinical Director for Acute, Rehabilitation and Forensic Secure Mental Health Services, Leicestershire Partnership Trust	Involved in the work by the Royal College of Psychiatry on developing a methodology in accrediting services. This has a link to the evidence which was reviewed at GC 8. (Declared at GC 8 – 25/01/17)	Personal non-financial (specific)	Declared and did not participate in any discussions or in writing any recommendations related to the specific evidence statement
Jonathan Senker	Chair of the Guideline Committee & Chief Executive of VoiceAbility	Chief Executive of VoiceAbility and Advocacy Experience (subsidiary company). They provide advocacy support to people with learning disabilities and challenging behaviour which is funded by local authorities, NHS, and private and voluntary providers. (Declared at recruitment)	Non-personal financial (specific)	Declared and reviewed at each meeting in relation to evidence on advocacy. Did not take part in discussions or in writing recommendations in relation to this topic area
Jonathan Senker	Chair of the Guideline Committee & Chief Executive of VoiceAbility	Trustee and Chair of Board for The Single Homes Project (SHP) (Declared at recruitment)	Personal non-financial (non-specific)	No action needed

Jonathan Senker	Chair of the Guideline Committee & Chief Executive of VoiceAbility	Has a sister who uses learning disability services (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Jonathan Senker	Chair of the Guideline Committee & Chief Executive of VoiceAbility	Father is a Trustee for Brighton & East Sussex Cross-Roads (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Karin Fuchs	Consultant Clinical Psychologist, West Sussex Learning Disability Services, Sussex Partnership NHS Trust	Attended stakeholder workshop as part of the new NHS England service model guideline (Declared at recruitment)	Non-personal financial (specific)	Declared and participated
Karin Fuchs	Consultant Clinical Psychologist, West Sussex Learning Disability Services, Sussex Partnership NHS Trust	Member of the Advisory Group for Intensive support (NHS England, Transforming Care) (Declared at GC 5 – 10/08/16)	Personal non-financial (non-specific)	Declared and participated
Laura Searle	Deputy Head, Avalon Special School, Street, Somerset	None		No action needed
Lisa Hopkins	Executive Director of Practice Development, Dimensions UK (until Sept 16)	Trustee for Autism Schools Trust (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Lisa Hopkins	Chief Executive, SeeAbility (from 12/09/16)	Works for an organisation who provides services for people in congregate and non-congregate settings (Declared at GC 4 – 01/06/16)	Non-personal financial (specific)	Declared and participated
Lisa Hopkins	Chief Executive, SeeAbility	Co-authored papers included in the review at GC 6 (Declared at GC 6 – 03/10/16)	Personal non-financial (specific)	Declared and did not participate in any discussions or in writing

				any recommendations related to the specific evidence statement
Mark Harvey	Head of Social Work & Communities and Principle Social Worker, Hertfordshire County Council	Co-Chair of the Social Workers Network (Declared at GC 8 – 25/01/17)	Personal non-financial (non-specific)	Declared and participated
Melanie Bruce	Highly Specialist Clinical Psychologist and Lead, Norfolk Community Health and Care NHS Trust	None		No action needed
Naomi Sills	Team Manager, Countywide Transitions	Co-authored papers included in the review at GC 6 (Declared at GC 6 – 03/10/16)	Personal non-financial (specific)	Declared and did not participate in any discussions or in writing any recommendations related to the specific evidence statement
Pam Bebbington	Expert by experience	Trustee of My Life My Choice (from Feb 2016 – Nov 2017)	Personal non-financial (non-specific)	Declared and participated
Pam Bebbington	Expert by experience	Doing some voluntary work for the Care Quality Commission (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Pam Bebbington	Expert by experience	Paid Consultant for My Life My Choice. (Declared at GC 13 – 12/12/17)	Personal financial (non-specific)	Declared and participated
Paul Scarrott	Expert by experience	Trustee of My Life My Choice and is paid for	Personal non-	Declared and

		various pieces of work. (Declared at recruitment)	financial (non-specific)	participated
Paul Scarrott	Expert by experience	Doing some voluntary work for the Care Quality Commission (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Rafik Hamazia	Expert by experience	Part of the Secure Care Community Service Model Working Group as a Consultant (chaired by NHS England) (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Rafik Hamazia	Expert by experience	Member of the Expert Reference Group Consultant for recommendations for Southern Health Foundation Trust (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Richard Hastings	Professor, Centre for Educational Development, Appraisal and Research, University of Warwick	Wife is a Cognitive Behaviour Therapist in a CAMHS service (NHS in Wales) (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Richard Hastings	Professor, Centre for Educational Development, Appraisal and Research, University of Warwick	Employed by University of Warwick. University receives funding under a research grant from NIHR (SSCR) to evaluate a brief staff training intervention focused on empathy towards people with challenging behaviour (Declared at recruitment)	Non-personal financial (specific)	Declared and participated
Richard Hastings	Professor, Centre for Educational Development, Appraisal and Research, University of	Currently undertaking research from NISCHR (Wales) to evaluate mindfulness based intervention for adults with learning disabilities	Non-personal financial (specific)	Declared and participated

	Warwick	with anger/aggression problems, and from the Sharland Foundation to support a UK research and practice network on behavioural intervention methods with children and adults with learning disability/autism (including Positive Behavioural Support) (Declared at recruitment)		
Richard Hastings	Professor, Centre for Educational Development, Appraisal and Research, University of Warwick	Lead member of UK Positive Behavioural Support Academy that produced a PBS competencies framework released under a Creative Commons license. Is also doing other work in relation to this, producing other resources based on this competencies framework. (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Richard Hastings	Professor, Centre for Educational Development, Appraisal and Research, University of Warwick	Research advisor to Brain in Hand, Ambitious about Autism, Sibs and Positive Behavioural Solutions Ltd (a social enterprise) (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Richard Hastings	Professor, Centre for Educational Development, Appraisal and Research, University of Warwick	Committee membership: NICE Guideline Development Group for the Mental Health and Learning Disabilities (2014-2016); Skills for Health Learning Disabilities Core Skills Education and Training Framework Steering Group (2015-2016); NHS England Midlands	Personal non-financial (specific)	Declared and participated

		<p>and East Regional Transforming Care Board (2015-2016); Learning Disability Transforming Care Service Model Reference Group (NHS England, Local Government Association, ADASS), (2015); Chair of the Royal Mencap Society External Advisory Forum (2014 –); Mencap Cymru Advisory Board (2015 -); Independent chair (appointed by NIHR HTA) of the Trial Steering Committee for an Epilepsy management in adults with learning disabilities RCT (PI H. Ring, Cambridge), (2014 – 2016); Independent chair (appointed by NIHR HS&DR) of the Study Steering Committee of the project “Mapping and evaluating Specialist Autism Team service models” (PI B. Beresford, York), (2014-2016); Trustee for the Royal Mencap Society (2009 - 2015)</p> <p>(Declared at recruitment)</p>		
Richard Hastings	Professor, Centre for Educational Development, Appraisal and Research, University of Warwick	<p>Co-authored the following papers which were included in the evidence review at GC 3:</p> <p>Griffith G M, and Hastings R P. (2014). 'He's hard work, but he's worth it'. The experience of</p>		Declared and did not participate in any discussions or in writing any recommendations related to the specific

		<p>caregivers of individuals with intellectual disabilities and challenging behaviour: a meta-synthesis of qualitative research. Journal of Applied Research in Intellectual Disabilities, 27(5), pp.401-419.</p> <p>Griffith G M, Hutchinson Li, and Hastings R P. (2013). "I'm not a patient, I'm a person": The experiences of individuals with intellectual disabilities and challenging behavior—A thematic synthesis of qualitative studies. Clinical Psychology: Science and Practice, 20, pp.469-488.</p> <p>(Declared at GC 3 – 12/04/16)</p>		evidence statement
Rowena Tye	Carer	<p>Member and Trustee of HF Trust which is a charity supporting adults with learning disabilities. Rowena's son who has a learning disability is also supported by this charity.</p> <p>(Declared at recruitment)</p>	Personal non-financial (specific)	Declared and participated
Rowena Tye	Carer	<p>Rowena's son uses congregate services</p> <p>(Declared at GC 4 – 01/06/16)</p>	Personal non-financial (specific)	Declared and participated
Sharon Jeffreys	Chief Commissioning Manager Mental Health, Learning Disabilities and Autism, South West Lincolnshire	<p>Member of the Expert Reference Group for Transforming Care</p> <p>(Declared at GC 9 – 09/03/17)</p>	Personal non-financial (non-specific)	Declared and participated

	Clinical Commissioning Group			
Veronique Kaboha	Carer	Independent expert by experience working on care and treatment reviews (Declared at recruitment)	Personal financial (non-specific)	Declared and participated
Veronique Kaboha	Carer	Member of Lambeth Parents Forum (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Carer	Member of Parents Special Interest Group by UK Society for Behavioural Analysis (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Carer	Affiliate member of UK-SBA (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Carer	Written some articles about own personal experience and other parents' experience of working with Applied Behaviour Analysis which have been published by the campaign ABAaccess4ALL (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Carer	Commented on posts on the ABAaccess4ALL Facebook campaign page (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Carer	Runs a campaign to improve autism education locally - The Hub Lambeth (Declared at	Personal non-financial (non-specific)	Declared and participated

		recruitment)		
Veronique Kaboha	Carer	Has given talks in the last year about own personal experience of being a parent of a child with learning disability and challenging behaviour to the following organisations: NHS England, North West London NHS and Kingston University (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Veronique Kaboha	Carer	Member of the London Learning Disability Workforce Network organised by the Health Education England London offices. (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Veronique Kaboha	Carer	Member of Focus South London (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Chief Executive of The Challenging Behaviour Foundation (CBF). The Charity Commission gave permission for Vivien to be appointed in a paid role as CEO. However, from 1st January 2017- 1st July 2017 her role was only paid 50% with 50% of it as voluntary, and from 1st July 2017 – 31st January 2018 it is entirely voluntary / unpaid. (Declared at recruitment and updated on 18/01/18)	Personal financial (specific)	Declared and participated. It was agreed that this was not a conflict of interest, as Vivien acknowledged that CBF would not gain any financial benefits from the recommendations drafted,
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Trustee and Co-founder of The Challenging Behaviour Foundation (CBF)	Personal non-financial (specific)	Declared and participated

		(Declared at recruitment)		
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Member of the NICE Quality Standards Advisory Committee for Challenging behaviour and learning disabilities (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Member of the Transforming Care Assurance Board (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Member of the Learning Disability Medicines Oversight Group (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Member of the Learning Disabilities Change and Improvement Steering Group (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Member of the CQC Learning Disabilities Advisory Group (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Member of the Hassiotis UCL PBS Research Group (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Member of the Tizard E-Pats Fellowship Steering Group (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Member of the CDC Restrictive Physical Intervention Steering Group (Declared at	Personal non-financial (non-specific)	Declared and participated

		recruitment)		
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	The Challenging Behaviour Foundation wrote one of the papers which was reviewed at GC 7 Declared at GC 7 – 22/11/16)	Personal non-financial (specific)	Declared and did not participate in any discussions or in writing any recommendations related to the specific evidence statement
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	CBF's involvement in the Channel 4 Dispatches documentary 'Under lock and key' – provided information to Ch4, supported two of the families featured in the documentary and also attended a roundtable discussion at Channel 4 (Declared at GC9 – 09/03/17)	Personal non-financial (specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Provided evidence to the National Audit Office and attended meetings with their team (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Issued a joint statement with Mencap about the NAO report (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Given evidence at the Public Accounts Committee (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Submitted evidence to the Calderstones closure consultation, and to the Lenehan review about residential schools for children with	Personal non-financial (specific)	Declared and participated

		learning disabilities who display behaviour described as challenging (Declared at GC9 – 09/03/17)		
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Attended the Transforming Care Children and Young People group (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Submitted evidence to the CAMHS service specification consultation (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Chief Executive, Challenging Behaviour Foundation	Member of the expert reference group of the Building the Right Support Evaluation (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated

Date last reviewed: 23/03/18