

Membership of Care and support of older people with learning disabilities Guideline Committee

The Committee will operate as an advisory Committee to NICE's Board, developing a guideline on care and support of older people with learning disabilities

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

The Committee has 17 core members.

Membership list

Name	Job Title, Organisation
Chair	
Margaret Lally	Former Director of UK Service Development, British Red Cross (retired 2013)
Vice-chair	
Philippa Russell	Former Chair of the Government's Standing Commission on Carers
Core members / Members	
Carol Walker	Former Professor of Social Policy, University of Lincoln (retired 2015)
Dawn Wiltshire	Expert by experience
Emma Killick	Director of Adult Services, MacIntyre
Erin Outram	Business Development- Safeguarding, MCA & DoLS, North Yorkshire County Council
Jan Hoskins	Clinical Case Manager and Continuing Health Care Lead Nurse for people with Learning Disabilities, NHS Clinical Commissioning Group
Jenny Anderton	Social worker and social service senior manager
Jenny Garrigan	Learning disability nurse and Executive Director of social care charity and provider for people with a learning disability
Jill Foalks	Carer
Jill Rasmussen	Clinical Lead for Dementia Royal College of General Practitioners; Clinical Lead Dementia SE Clinical Network NHS England; Independent Consultant
Lisa Birtles-Smith	Clinical Lead, Learning Disabilities, NHS Clinical Commissioning Group
Michael Brookstein	Expert by experience
Patricia Charlesworth	Expert by experience
Simon Jones	Lead Behavioural Practitioner for Consensus, part of the Caring Homes group
Stephen Elsmere	Carer
Topic expert members	<u> </u>
Laurence Taggart	Lead for the Centre for Intellectual and Developmental Disabilities & Lead for the Autism Research Hub, Institute of

Nursing and Health Research,
Ulster University

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
Carol Walker	Professor of Social Policy, University of Lincoln (retired 2015)	Trustee of Sheffield Mencap and Gateway - organistion providing services to people with learning disabilities, including older people and their family carers (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Carol Walker	Professor of Social Policy, University of Lincoln (retired 2015)	Written extensively on policies concerning older people with learning disabilities and family carers, in which policy and practice has been critically assessed (Declared at recruitment)	Personal non-financial (specific)	participated
Dawn Wiltshire	Expert by experience	Trustee of My Life, My Choice (until Dec 2017) (Declared at recruitment)	Personal non-financial (non- specific)	Declared and participated
Dawn Wiltshire	Expert by experience	Paid Consultant for My Life My Choice. (Declared at GC 14 – 18/01/18)	Personal financial (non- specific)	Declared and participated
Emma Killick	Director of Adult Services, MacIntyre	MacIntyre is a Registered Charity, established in 1966, which provides a range of services (residential, supported living, educational, outreach and respite) for children and adults with learning disabilities across England and Wales. The Charity currently supports around 1300 people and employs approximately 2600 staff. MacIntyre	Non- personal financial (specific)	Declared and participated

		currently works with over 70 different Local Authorities and CCGs to deliver services which are regulated by CQC, CSSIW and Ofsted as appropriate (Declared at recruitment)		
Emma Killick	Director of Adult Services, MacIntyre	Member of the Encourage Independent Living Committee with Grand Union Housing Group. (Declared at GC 14 – 18/01/18)	Personal financial (non- specific)	Declared and participated
Erin Outram	Business Development- Safeguarding, MCA & DoLS, North Yorkshire County Council	Member of the Advisory panel for NHS Accessible information standard (Declared at recruitment)	Personal non-financial (non- specific)	Declared and participated
Jan Hoskins	Clinical Case Manager and Continuing Health Care Lead Nurse for people with Learning Disabilities, NHS Clinical Commissionin g Group	None		No action needed
Jenny Anderton	Social worker and Social service Senior Manager	Owns and manages a consultancy company in Health and social care (Declared at recruitment)	Personal financial (non- specific)	Declared and participated
Jenny Garrigan	Learning disability nurse and Executive Director of social care charity and provider for people with a learning	Executive Director of Thera Trust, registered charity and parent company of Thera Group. Thera Group provides social care and support for people with learning disabilities.	Non- personal financial (specific)	Declared and participated

	disability			
		(Declared at recruitment)		
Jill Foalks	Carer	None		No action needed
Jill Rasmussen	Clinical Lead for Dementia Royal College of General Practitioners	Clinical Lead for Dementia for RCGP; Member of Intellectual Disability Special Interest Group at Royal College General Practitioners	Personal non-financial (non- specific)	Declared and participated
Jill Rasmussen	Clinical Lead Dementia SE Clinical Network NHS England	Advising and educating about NHS Standards, best practice and models of care across Kent, Surrey and Sussex (Declared at recruitment)	Personal financial (non- specific)	Declared and participated
Jill Rasmussen	Independent Consultant	Director and Co- founder of psi-napse. psi-napse is an independent consultancy specialising in advising about psychiatry and neurology research; CNS strategic drug development, medico marketing and education; venture capital providers about potential investments in the CNS sector (Declared at recruitment)	Personal financial (non- specific)	Declared and participated
Laurence Taggart	Lead for the Centre for Intellectual and Developmental Disabilities & Lead for the Autism Research Hub, Institute of Nursing and Health Research, Ulster University	Member of the Royal College of Nursing Learning Disability Forum (Declared at recruitment)	Personal non-financial (specific)	Declared and participated

Laurence	Lead for the	Co-authored the	Personal	Declared
Taggart	Centre for	following papers that	non-financial	
	Intellectual and	were reviewed as part	(specific)	participate in
	Developmental Disabilities &	of the evidence-base:		any discussions
	Lead for the	McIlfatrick, S. J.,		or in writing
	Autism	Taggart, L. &		any
	Research Hub,	Truesdale-Kennedy, M.		recommend
	Institute of	N. (2011): Supporting		ations
	Nursing and Health	women with intellectual disabilities to access		related to the specific
	Research,	breast cancer		evidence
	Ulster	screening: a health		statement
	University	care professional perspective. European		
		Journal of Cancer		
		Care, 20,412 – 420.		
		Trucodolo Konzedu M		
		Truesdale-Kennedy, M. N., Taggart, L. &		
		McIlfatrick, S. J. (2011):		
		Breast cancer		
		knowledge among women with intellectual		
		disabilities and their		
		experiences of breast		
		mammography. Journal		
		of Advanced Nursing, 67 (6), 1294 – 1304.		
		Taggart, L., Truesdale-		
		Kennedy, M., Ryan, A. & McConkey, R.		
		(2012): Examining the		
		support needs of		
		ageing family carers in		
		developing future plans for a relative with an		
		intellectual disability.		
		Journal of Intellectual		
		Disabilities, 16 (3), 217-		
		234.		
		Ryan, A., Taggart, L. &		
		Truesdale-Kennedy, M.		
		(2014): Issues in caregiving for older		
		people with intellectual		
		disabilities and their		
		ageing family carers: a		
		review and commentary. The		
		International Journal of		
		Older People Nursing,		

		9 (3). pp. 217-226.]
		o (0). pp. 217 220.		
		Taggart, L. & Cousins, W. (Eds) (2014): Health Promotion for People with Intellectual Disabilities. Open University Press/McGraw-Hill Publishers: Maidenhead, England. ISBN: 9780335246946.		
		McConkey, T., Taggart, L. & Kane, M (2015): Optimising the uptake of health checks for people with intellectual disabilities. Journal of Intellectual Disabilities, 19(3), 205-214.		
		(Declared at GC 1 – 01/02/16)		
Lisa Birtles- Smith	Clinical Lead, Learning Disabilities, NHS Clinical Commissionin g Group	None		No action needed
Margaret Lally	Guideline Committee Chair	Trustee of Heritage Care which provides support to people with learning disabilities and older people (Declared at recruitment)	Personal non-financial (non- specific)	Declared and participated
Michael Brookstein	Expert by	None		No action needed
Patricia Charlesworth	experience Expert by experience	Member of Foundation for People with Learning Disabilities Advisory Group and represents the Foundation at various meetings	Personal non-financial (non- specific)	Declared and participated
		(Declared at recruitment)		
Patricia Charlesworth	Expert by experience	Member of the GOLD group (growing older with learning	Personal non-financial (specific)	Declared and participated

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		disabilities) which was		
		established by the		
		foundation		
		(Declared at recruitment)		
Patricia	Expert by	Member of Hackney	Personal	Declared
Charlesworth	experience	People First	non-financial	
			(non-	participated
		(Declared at	specific)	
Detrivity	F	recruitment)	D	D
Patricia	Expert by	Member of National	Personal	Declared
Charlesworth	experience	Forum for people with a	non-financial	and
		learning disability	(specific)	participated
Patricia	Export by	(Recruitment) Member of National	Personal	Declared
Charlesworth	Expert by experience	council for Palliative	non-financial	and
Chanesworth	cypenence	Care and the National	(non-	participated
		Valuing families Forum	specific)	participated
			opeoine)	
		(Declared at recruitment)		
Philippa	Former chair of	Trustee/Board member	Personal	Declared
Russell	the	of the National	non-financial	and
	Government's	Development Team for	(non-	participated
	Standing	Inclusion	specific)	
	Commission			
	on Carers	(Declared at recruitment)		
Philippa	Former chair of	Trustee/Board member	Personal	Declared
Russell	the	of SEEFA (South East	non-financial	
1 (dooon	Government's	England Forum on	(non-	participated
	Standing	Ageing)	specific)	participated
	Commission		op c cc)	
	on Carers	(Declared at		
		recruitment)		
Philippa	Former chair of	Trustee/Board member	Personal	Declared
Russell	the	of the National Family	non-financial	and
	Government's	Carers Network	(non-	participated
	Standing		specific)	
	Commission	(Declared at		
	on Carers	recruitment)		
Philippa	Former chair of	Trustee/Board member	Personal	Declared
Russell	the	of the Think Local, Act	non-financial	and
	Government's	Personal Partnership	(non-	participated
	Standing Commission	(Declared at	specific)	
	on Carers	(Declared at recruitment)		
Philippa	Former chair of	Member of the Advisory	Personal	Declared
Russell	the	Board (no executive or	non-financial	and
	Government's	trustee role, adviser on	(non-	participated
	Standing	policy only) for the	specific)	participation
	Commission	Montreux Healthcare		
	on Carers	Partnership. The		
		· · · · · · · · · · · · · · · · · · ·		

Philippa Russell	Former chair of the Government's	partnership is an independent Swiss and UK-based organisation seeking to develop new community-based housing options for people with learning disabilities and complex needs (Declared at recruitment) Member of the Overview Advisory Board for NHS	Personal non-financial (non-	Declared and participated
	Standing Commission on Carers	England's Commitment to Carers programme (Recruitment)	specific)	
Philippa Russell	Former chair of the Government's Standing Commission on Carers	Member of ADASS Carers Policy Network (Declared at recruitment)	Personal non-financial (non- specific)	Declared and participated
Philippa Russell	Former chair of the Government's Standing Commission on Carers	Periodic participation as 'expert by experience' in NHS England Care and Treatment Reviews (Declared at recruitment)	Personal non-financial (non- specific)	Declared and participated
Philippa Russell	Former chair of the Government's Standing Commission on Carers	Patron/Vice-President of Carers UK (Declared at recruitment)	Personal non-financial (non- specific)	Declared and participated
Simon Jones	Learning disability nurse and Head of Behavioural Support at social care provider, supporting individuals living in supported housing or residential care	Chair of Royal College of Nursing Learning Disability forum (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Simon Jones	Learning	Advisor to Care Quality	Personal	Declared

	disability nurse and Head of Behavioural Support at social care provider, supporting individuals living in supported housing or residential care	Commission and Parliamentary and Health Service Ombudsman (Declared at recruitment)	non-financial (non- specific)	and participated
Stephen Elsmere	Carer		Personal non-financial (non- specific)	Declared and participated

Date last reviewed: 23/03/18