

Disabled children and young people up to 25 with severe complex needs Committee meeting

Date: 03/07/2019 and 04/07/2019

Location: Royal College of Obstetricians and Gynaecologists (RCOG),
London

Minutes: FINAL

Committee members present:		
David Croisdale-Appleby (Chair)		Present for notes 1-6
Clare Allen-Mulroy		Present for notes 1-6
Wendy Brotherton		Present for notes 1-6
Caroline Coady (Topic Advisor, Social Care)		Present for notes 1-6
Rosie Hallett		Present for notes 1-6
Judith James (day 2 only)		Present for notes 4-6
Yasmin Khan (Topic Advisor, Health Care)		Present for notes 1-6
Branwen Mann		Present for notes 1-6
Lauren Roberts		Present for notes 1-6
Theodor Sergiou		Present for notes 1-6
Katherine Taylor		Present for notes 1-6
Dominic Wall (Topic Advisor, Education)		Present for notes 1-6
Trudy Ward		Present for notes 1-6
Elizabeth Stanley (Co-opted member; day 2 only)		Present for notes 4-6
Jonathan Higham (Co-opted member; day 1 only)		Present for notes 1-4

In attendance:		
Simran Chawla (day 1 only)	NICE Public Involvement Adviser	Present for notes 1-4
Clifford Middleton (day 1 only)	NICE Guidelines Commissioning Manager	Present for notes 1-5
Nathan Bromham	National Guideline Alliance (NGA) Senior Systematic Reviewer	Present for notes 1-6
Preetpal Doklu (day 1 only)	NGA Business Administrator	Present for notes 1-4
Katharina Dworzynski (day 1)	NGA Guideline Lead	Present for notes 1-4

only)		
James Gilbert	NGA Head of Evidence Reviews	Present for notes 4-6
Katriona O'Donoghue	NGA Systematic Reviewer	Present for notes 1-6
Samuel Perwaiz	NGA Project Manager	Present for notes 1-6
Timothy Reeves	NGA Information Scientist	Present for notes 1-6
Eric Slade (day 1 only)	NGA Senior Health Economist	Present for notes 1-4
Bridget Warr	NGA Social Care Advisor	Present for notes 1-6

Observers:	
None	

Apologies:	
Louisa Joyce	Committee member
Jacqui Turner	Committee member
Moira Mugglestone	NGA Director of Methodology

<p>1. Welcome and objectives for the meeting</p> <p>The Chair welcomed the Committee members and attendees to the first meeting on Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education. The Committee members and attendees introduced themselves.</p> <p>The Chair informed the Committee that apologies had been received. These are noted above.</p> <p>The Chair outlined the objectives of the meeting, which included:</p> <ul style="list-style-type: none"> • establishing effective working of the committee • briefing the committee on the finalised scope and methods used to develop NICE service delivery guidelines • agreeing the review questions • starting to draft review protocols.
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2. Confirmation of matter under discussion, and declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education.

The Chair asked everyone to verbally declare any interests.

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
David Croisdale-Appleby	Chair	Educational visitor, General Medical Council	Direct – financial	Declare and participate Agreed by NGA guideline lead, September 2018 Not specific to guideline topic
David Croisdale-Appleby	Chair	Professor of Corporate Strategy, University of Durham Business School	Direct – financial	Declare and participate Agreed by NGA guideline lead, September 2018 Not specific to guideline topic
David Croisdale-Appleby	Chair	Specialist reviewer, Medical Research Council	Direct – financial	Declare and participate Agreed by NGA guideline lead, September 2018 Not specific to guideline topic
David Croisdale-	Chair	Director, Health Education England	Direct – financial	Declare and participate

Appleby				<p>Agreed by NGA guideline lead, September 2018</p> <p>Not specific to guideline topic</p>
David Croisdale-Appleby	Chair	Professor of Health and Human Sciences, Manchester Metropolitan University	Direct – financial	<p>Declare and participate</p> <p>Agreed by NGA guideline lead, September 2018</p> <p>Not specific to guideline topic</p>
David Croisdale-Appleby	Chair	Professor of Social Policy and Social Work, University of Huddersfield	Direct – financial	<p>Declare and participate</p> <p>Agreed by NGA guideline lead, September 2018</p> <p>Not specific to guideline topic</p>
David Croisdale-Appleby	Chair	Professor of Medical Education, University of Aberdeen	Direct – financial	<p>Declare and participate</p> <p>Agreed by NGA guideline lead, September 2018</p> <p>Not specific to guideline topic</p>
David Croisdale-Appleby	Chair	Council member and specialist reviewer, Association of Medical Educators	Direct – financial	<p>Declare and participate</p> <p>Agreed by NGA guideline lead, September</p>

				2018 Not specific to guideline topic
David Croisdale-Appleby	Chair	Chair, Royal College of Physicians	Direct – financial	Declare and participate Agreed by NGA guideline lead, September 2018 Not specific to guideline topic
David Croisdale-Appleby	Chair	Professor of Health and Clinical Education, University of Derby	Direct – financial	Declare and participate Agreed by NGA guideline lead, September 2018 Not specific to guideline topic
David Croisdale-Appleby	Chair	Honorary ambassador for the UK for the Nelson Mandela Legacy, the Children’s Hospital in South Africa serving the 15 nations of the Southern Africa Development Community	Direct – non-financial professional and personal	Declare and participate
David Croisdale-Appleby	Chair	Chair, Dementia UK	Direct – non-financial professional and personal	Declare and participate
David Croisdale-Appleby	Chair	Chair, UK Government Advisory Group on Carers, and Ministerial	Direct – non-financial professional and personal	Declare and participate

		adviser for the Department of Health and Social Care		
David Croisdale-Appleby	Chair	Chair, Science Council	Direct – non-financial professional and personal	Declare and participate
David Croisdale-Appleby	Chair	Professor of Medicine, Health and Social Care, University of Lincoln	Direct – non-financial professional and personal	Declare and participate
David Croisdale-Appleby	Chair	Chair, University of Durham Business School Advisory Committee	Direct – non-financial professional and personal	Declare and participate
Clare Allen-Mulroy	Lay Member	Service user member, Neurokey charity	Direct – non-financial professional and personal	Declare and participate
Wendy Brotherton	Advanced Speech and Language Therapist, Harrogate and District NHS Foundation Trust	Investor in fund managed by a financial advisor; can request where money is invested but no investment in commercial companies relevant to the guideline topic	Direct - financial	Declare and participate Agreed by NGA guideline lead, July 2019 Not specific to guideline topic
Wendy Brotherton	Advanced Speech and Language Therapist, Harrogate and District NHS Foundation Trust	Makaton regional tutor	Direct – non-financial professional and personal	Declare and participate
Wendy Brotherton	Advanced Speech and Language Therapist, Harrogate and	Committee member, North Yorkshire County Council guidance on	Direct – non-financial professional and personal	Declare and participate

	District NHS Foundation Trust	visual support for learning and communication		
Wendy Brotherton	Advanced Speech and Language Therapist, Harrogate and District NHS Foundation Trust	Member, Yorkshire Speech and Language Therapy Learning Disability Clinical Excellence Network	Direct – non-financial professional and personal	Declare and participate
Wendy Brotherton	Advanced Speech and Language Therapist, Harrogate and District NHS Foundation Trust	Member, Yorkshire Alternative and Augmentative Communication Clinical Excellence Network	Direct – non-financial professional and personal	Declare and participate
Wendy Brotherton	Advanced Speech and Language Therapist, Harrogate and District NHS Foundation Trust	Member, Health and Care Professions Council (HCPC)	Direct – non-financial professional and personal	Declare and participate
Wendy Brotherton	Advanced Speech and Language Therapist, Harrogate and District NHS Foundation Trust	Member, Royal College of Speech and Language Therapy	Direct – non-financial professional and personal	Declare and participate
Caroline Coady (formerly Bennett)	Assistant Director - Social Care, Council for Disabled Children, National Children's Bureau, London	Co-author, '21st Century Social Work'	Direct – non-financial professional and personal	Declare and participate
Caroline Coady (formerly)	Assistant Director - Social Care, Council for	Involved in Accelerated Working groups	Direct – non-financial professional	Declare and participate

Bennett)	Disabled Children, National Children's Bureau, London	on Social Care training	and personal	
Caroline Coady (formerly Bennett)	Assistant Director - Social Care, Council for Disabled Children, National Children's Bureau, London	Development and delivery of training related to social care and education, health and care (EHC) plans	Direct – non-financial professional and personal	Declare and participate
Caroline Coady (formerly Bennett)	Assistant Director - Social Care, Council for Disabled Children, National Children's Bureau, London	Member of working group on liberty protection safeguards with the Department for Education	Direct – non-financial professional and personal	Declare and participate
Caroline Coady (formerly Bennett)	Assistant Director - Social Care, Council for Disabled Children, National Children's Bureau, London	Co-applicant on transition research programme awarded to the Northumbria Healthcare NHS Foundation Trust and Newcastle University, funded by the National Institute for Health Research (NIHR)	Direct – non-financial professional and personal	Declare and participate
Rosie Hallett	Senior Lecturer in Occupational Therapy, Kingston University and St Georges, University of London	Senior lecturer on occupational therapy pre-registration course, Kingston University and St Georges University of London (mainly a teaching	Direct - financial	Declare and participate Agreed by NGA guideline lead, June 2019 Not specific to guideline topic

		position, no research involvement as yet)		
Judith James	Independent Education Advisor, Education and Case Management Services Ltd, Gateshead	Independent adviser and expert witness on educational services for children and young people with an acquired brain injury to solicitors, case management companies and schools	Direct - financial	Declare and participate Agreed by NGA guideline lead, June 2019 Not specific to guideline topic (to be kept under review during development of the guideline)
Louisa Joyce	Transition Coordinator, Cheshire East Council	Transition Coordinator, Cheshire East Council, which involves offering social care advice in relation to young people in transition to the Special Educational Needs and Disabilities Implementation Board, the Special Educational Needs and Disabilities Panel and the Children with Disabilities Panel	Direct - financial	Declare and participate Agreed by NGA guideline lead, June 2019 Employment in public sector
Louisa Joyce	Transition Coordinator, Cheshire East Council	Part-time lecturer, Staffordshire University, which involves delivering guest lectures to	Direct - financial	Declare and participate Agreed by NGA guideline lead, June 2019

		students (one 4-hour lecture delivered this year) and acting as Practice Educator to a social work student		Employment in public sector
Yasmin Khan	Consultant Paediatrician in Neurodisability, Chailey Clinical Services, North Chailey, East Sussex	Private practice providing clinical care for children with cerebral palsy at a school for children with disabilities (8 days per year); paid a fee for each session completed	Direct - financial	Declare and participate Agreed by NGA guideline lead, October 2018 Only undertakes procedures that would be part of NHS practice
Yasmin Khan	Consultant Paediatrician in Neurodisability, Chailey Clinical Services, North Chailey, East Sussex	Investor in fund managed by a financial advisor; can request where money is invested but no investment in commercial companies relevant to the guideline topic	Direct - financial	Declare and participate Agreed by NGA guideline lead, October 2018 Not specific to guideline topic
Yasmin Khan	Consultant Paediatrician in Neurodisability, Chailey Clinical Services, North Chailey, East Sussex	Medical lead for Young Epilepsy, a national charity for young people with epilepsy	Direct - financial	Declare and participate Agreed by NGA guideline lead, July 2019 Not specific to guideline topic
Yasmin Khan	Consultant Paediatrician in Neurodisability, Chailey Clinical Services, North Chailey, East Sussex	Member (non-executive director) of the Board of Surrey and Sussex Healthcare NHS Trust	Direct - financial	Declare and participate Agreed by NGA guideline lead, July 2019 Not specific to

				guideline topic
Yasmin Khan	Consultant Paediatrician in Neurodisability, Chailey Clinical Services, North Chailey, East Sussex	Has published research relevant to the guideline topic	Direct – non-financial professional and personal	Declare and participate Agreed by NGA guideline lead, October 2018 Research published more than 10 years before guideline development started and no public statement of opinion specific to guideline topic included
Yasmin Khan	Consultant Paediatrician in Neurodisability, Chailey Clinical Services, North Chailey, East Sussex	Trustee of Martlets Hospice in Hove which provides palliative and end of life care for adults	Direct – non-financial professional and personal	Declare and participate
Branwen Mann	Lay Member	Stakeholder with Medicines and Healthcare products Regulatory Agency for sodium valproate	Direct – financial	Declare and participate Agreed by NGA guideline lead, July 2019 Not specific to guideline topic
Branwen Mann	Lay Member	Involved in Independent Medicines and Medical Devices Safety Review for Primodos, vaginal mesh implants and sodium valproate (judge-led	Direct – financial	Declare and participate Agreed by NGA guideline lead, July 2019 Not specific to guideline topic

		inquiry)		
Branwen Mann	Lay Member	General interest in fetal valproate syndrome	Direct – non-financial professional and personal	Declare and participate
Lauren Roberts	Director of Support, Genetic Alliance UK	Member, Solve RD EBCD project group and CETG	Direct – non-financial professional and personal	Declare and participate
Lauren Roberts	Director of Support, Genetic Alliance UK	Member, Genomics England CYP literature review group	Direct – non-financial professional and personal	Declare and participate
Lauren Roberts	Director of Support, Genetic Alliance UK	Co-applicant, NIHR RFPB grant proposal related to service user experiences of the new genomic medicine service (in application stage)	Direct – non-financial professional and personal	Declare and participate
Lauren Roberts	Director of Support, Genetic Alliance UK	Advisory team member, NIHR Senior Fellowship application (in application stage)	Direct – non-financial professional and personal	Declare and participate
Lauren Roberts	Director of Support, Genetic Alliance UK	Advisory team member, Wellcome Fellowship application (in application stage)	Direct – non-financial professional and personal	Declare and participate
Lauren Roberts	Director of Support, Genetic Alliance UK	Working with NHS England Genomics Team to literature for service users	Direct – non-financial professional and personal	Declare and participate
Lauren Roberts	Director of Support, Genetic Alliance UK	Genetic Alliance UK receives funding from	Indirect	Declare and participate

		commercial companies		
Theodor Sergiou	Lay Member	General interest in developing health care for children and young people	Direct – non-financial professional and personal	Declare and participate
Katherine Taylor	Senior Commissioning Manager (Children's), NHS Devon Clinical Commissioning Group	Children Senior Commissioning Manager and strategic lead for SEND, NHS Devon Clinical commissioning Group	Direct – financial	Declare and participate Agreed by NGA guideline lead, June 2019 Employment in public sector
Katherine Taylor	Senior Commissioning Manager (Children's), NHS Devon Clinical Commissioning Group	Member, Chartered Society of Physiotherapy	Direct – non-financial professional and personal	Declare and participate
Katherine Taylor	Senior Commissioning Manager (Children's), NHS Devon Clinical Commissioning Group	Member, Association of Paediatric Chartered Physiotherapists	Direct – non-financial professional and personal	Declare and participate
Katherine Taylor	Senior Commissioning Manager (Children's), NHS Devon Clinical Commissioning Group	Member, HCPC	Direct – non-financial professional and personal	Declare and participate
Katherine Taylor	Senior Commissioning Manager (Children's), NHS Devon Clinical Commissioning Group	Company secretary, Bridgtown Cycles (non-dividends role)	Indirect	Declare and participate

Jacqui Turner	Commissioning Officer, Calderdale Metropolitan Borough Council, Halifax	Developed coproduced autism strategy involving local government council and clinical commissioning group	Direct – non-financial professional and personal	Declare and participate
Jacqui Turner	Commissioning Officer, Calderdale Metropolitan Borough Council, Halifax	Potential to be involved in autism pathway task and finish group within local government council	Direct – non-financial professional and personal	Declare and participate
Jacqui Turner	Commissioning Officer, Calderdale Metropolitan Borough Council, Halifax	Potential to be involved in autism training task and finish group within local government council	Direct – non-financial professional and personal	Declare and participate
Dominic Wall	Chief Executive Officer, The Southfield Grange Trust multi-academy trust, Bradford (until 31 May 2019) Executive Principal and Special Educational Needs and Disability Lead for the Co-op Academies Trust, Southfield, Bradford (from 1 June 2019)	Chief Executive Officer, The Southfield Grange Trust multi-academy trust, Bradford	Direct – financial	Declare and participate Agreed by NGA guideline lead, June 2019 Employment in public sector
Dominic Wall	Chief Executive Officer, The Southfield Grange Trust	Executive Principal, Co-op Academy Southfield and	Direct – financial	Declare and participate Agreed by

	<p>multi-academy trust, Bradford (until 31 May 2019)</p> <p>Executive Principal and Special Educational Needs and Disability Lead for the Co-op Academies Trust, Southfield, Bradford (from 1 June 2019)</p>	<p>Special Educational Needs and Disabilities Lead for The Co-op Academies Trust, Bradford</p>		<p>NGA guideline lead, June 2019</p> <p>Employment in public sector</p>
<p>Dominic Wall</p>	<p>Chief Executive Officer, The Southfield Grange Trust multi-academy trust, Bradford (until 31 May 2019)</p> <p>Executive Principal and Special Educational Needs and Disability Lead for the Co-op Academies Trust, Southfield, Bradford (from 1 June 2019)</p>	<p>Member of The Schools Forum, Bradford (academy representative)</p>	<p>Direct – non-financial professional and personal</p>	<p>Declare and participate</p>
<p>Dominic Wall</p>	<p>Chief Executive Officer, The Southfield Grange Trust multi-academy trust, Bradford (until 31 May 2019)</p> <p>Executive Principal and Special Educational Needs and</p>	<p>Member, Bradford District Achievement Partnership support group of special schools (as head teacher of Southfield School)</p>	<p>Direct – non-financial professional and personal</p>	<p>Declare and participate</p>

	Disability Lead for the Co-op Academies Trust, Southfield, Bradford (from 1 June 2019)			
Dominic Wall	Chief Executive Officer, The Southfield Grange Trust multi-academy trust, Bradford (until 31 May 2019) Executive Principal and Special Educational Needs and Disability Lead for the Co-op Academies Trust, Southfield, Bradford (from 1 June 2019)	Member, The Harmony Trust multi-academy trust, Oldham	Direct – non-financial professional and personal	Declare and participate
Dominic Wall	Chief Executive Officer, The Southfield Grange Trust multi-academy trust, Bradford (until 31 May 2019) Executive Principal and Special Educational Needs and Disability Lead for the Co-op Academies Trust, Southfield, Bradford (from 1 June 2019)	Executive committee member, Special Schools Voice representative group (Yorkshire and Humber regional representative)	Direct – non-financial professional and personal	Declare and participate
Dominic Wall	Chief Executive Officer, The	Member, Advisory Group	Direct – non-financial	Declare and participate

	<p>Southfield Grange Trust multi-academy trust, Bradford (until 31 May 2019)</p> <p>Executive Principal and Special Educational Needs and Disability Lead for the Co-op Academies Trust, Southfield, Bradford (from 1 June 2019)</p>	<p>of New College, Bradford (a sixth form college)</p>	<p>professional and personal</p>	
<p>Dominic Wall</p>	<p>Chief Executive Officer, The Southfield Grange Trust multi-academy trust, Bradford (until 31 May 2019)</p> <p>Executive Principal and Special Educational Needs and Disability Lead for the Co-op Academies Trust, Southfield, Bradford (from 1 June 2019)</p>	<p>Head teacher of special school selected as long-term collaborative partner to provide supported internships for sixth formers and school leavers with learning difficulties; contract partner with DFN Project SEARCH programme through the DFN Charitable Foundation</p>	<p>Indirect</p>	<p>Declare and participate</p>
<p>Trudy Ward</p>	<p>Area Head of Nursing and Governance, Sussex Community NHS Foundation Trust</p>	<p>Nursing advisory panel member, WellChild charity</p>	<p>Direct – financial</p>	<p>Declare and participate Agreed by NGA guideline lead, June 2019 Financial interest only in the context</p>

				of reasonable travelling expenses being reimbursed
Trudy Ward	Area Head of Nursing and Governance, Sussex Community NHS Foundation Trust	Steering group member, National Confidential Enquiry into Patient Outcomes and Death (related to children requiring long-term ventilation support)	Direct – financial	Declare and participate Agreed by NGA guideline lead, June 2019 Financial interest only in the context of reasonable travelling expenses being reimbursed
Elizabeth Stanley (co-opted member)	Director, Wraparound Partnership, Manchester	Director, Wraparound Partnership	Direct – financial	Declare and participate Agreed by NGA guideline lead, June 2019 Co-opted member not a voting member of the committee
Elizabeth Stanley (co-opted member)	Director, Wraparound Partnership, Manchester	Board member, Greater Manchester Health and Social Care Partnership Children and Young People Executive	Direct – financial	Declare and participate Agreed by NGA guideline lead, June 2019 Co-opted member not a voting member of the committee
Jonathan Higham (co-opted member)	GP, Bottisham Medical Practice, Cambridge	Partner, Bottisham Medical Practice, Cambridge	Direct – financial	Declare and participate Agreed by NGA guideline lead, June 2019

				Co-opted member not a voting member of the committee
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The Chair and a senior member of the Developer’s team noted that the interests declared did not prevent the attendees from fully participating in the meeting.

3. Minutes of last meeting

This was the first meeting and so there were no minutes to review.

4. Presentations

The Chair introduced Clifford Middleton, NICE Guidelines Commissioning Manager, who gave a presentation on an introduction to NICE guidelines. Clifford took questions from the group.

The Chair introduced Simran Chawla, NICE Public Involvement Adviser, who gave a presentation on an introduction to the NICE Public Involvement Programme. Simran took questions from the group.

The Chair introduced Katharina Dworzynski, NGA Guideline Lead, who gave presentations on an introduction from the NGA and declarations of interest. Katharina took questions from the group.

The Chair introduced Nathan Bromham, NGA Senior Systematic Reviewer, Timothy Reeves, NGA Information Scientist, and Eric Slade, NGA Senior Health Economist, who took questions from the group about online induction material and the guideline development process.

The Chair gave a presentation on the final guideline scope. The Chair took questions from the group.

The Chair introduced Preetpal Doklu, NGA Business Administrator, who gave a presentation on the NGA travel and expenses policy. Preetpal took questions from the group.

The Chair introduced Nathan Bromham, NGA Senior Systematic Reviewer, who gave a presentation on the draft review questions. Nathan took questions from the group.

The Chair introduced Nathan Bromham, NGA Senior Systematic Reviewer, Katriona O’Donoghue, NGA Systematic Reviewer, and James Gilbert, NGA Head of Evidence Reviews, who gave a presentation on drafting review protocols. Nathan, Katriona and James took questions from the group.

The Committee thanked Clifford, Simran, Katharina, Nathan, Timothy, Eric, Preetpal, Katriona and James for their presentations and contribution to the development of the guideline.

5. Questions and discussion

The Committee discussed the draft review questions and draft review protocols and were given the opportunity to ask questions.

6. Any other business

There was no other business.

Date of next meeting: 16/09/2019

Location of next meeting: RCOG, London