



# Experts by experience

## Directory for Transforming Care Partnerships

Health Education England, Skills for Care and Skills for Health are working with Transforming Care partners and other key stakeholders to support the ambitions of the Transforming Care programme. We're doing this by ensuring that we have a workforce which is able to effectively support people with a learning disability and/ or autism and behaviours of concern in the community.

We've produced a list of organisations which are led by or help people who are 'experts by experience' – people who have a learning disability or autism or family and friends. You can contact these organisations to help with the Transforming Care programme, particularly with the parts of it that are about workforce development.

Organisation's name	Geographical area covered	Membership group	Contact details	Special skills / knowledge	Other comments
National Forum of Families	England	Family and carers of people with learning disabilities, carers with a learning disability, organisations working with families and other allies who work to support families of people with learning disabilities.	<a href="mailto:lucyvirgo@inclusionnorth.org">lucyvirgo@inclusionnorth.org</a>	<p>They talk to the Government about the big issues and influences the work the Government does with family carers of people with a learning disability. They're interested in the impact of Transforming Care in the region and encourage the engagement of people with learning disabilities and their families in transforming care plans.</p> <p><b>Acknowledgement:</b> The funding for both the National Forum of People with Learning Disabilities and the National Valuing Families Forum ended at the end of March 2017. There are still organisations who were connected with the forums in the 9 regions in England who would be willing to get involved in the workforce work to support the transforming care programme.</p>	National forum

National Forum of People with Learning Disabilities	England	Self-advocates including those with complex needs, their supporters and self-advocacy organisations.	<a href="mailto:lucyvirgo@inclusionnorth.org">lucyvirgo@inclusionnorth.org</a>	<p>They listen to the voices of people with complex care needs and report back to local and national bodies. They're interested in the impact of Transforming Care in the region and encourage the engagement of people with learning disabilities and their families in transforming care plans.</p> <p><b>Acknowledgement:</b> The funding for both the National Forum of People with Learning Disabilities and the National Valuing Families Forum ended at the end of March 2017. There are still organisations who were connected with the forums in the 9 regions in England who would be willing to get involved in the workforce work to support the transforming care programme.</p>	National forum
Action on Disability - The Greswell Centre	London	People with a range of disabilities including physical disabilities, learning disabilities and/ or autism.	<a href="mailto:info@actiondisability.org.uk">info@actiondisability.org.uk</a>  Other contact: <a href="mailto:Sarah.Robinson@actiondisability.org.uk">Sarah.Robinson@actiondisability.org.uk</a>	They provide accessible activities to promote independent living and give disabled people the knowledge and confidence about their rights. They also support with employment, advocacy and benefits.	User led organisation

Advocacy in Greenwich	London	People with learning and physical disabilities, including self-advocates, and their families.	Anita - Director: <a href="mailto:anita@advocacyingreenwich.org.uk">anita@advocacyingreenwich.org.uk</a>  Other contacts: <a href="mailto:vicky@advocacyingreenwich.org.uk">vicky@advocacyingreenwich.org.uk</a>  <a href="mailto:Robert@advocacyingreenwich.org.uk">Robert@advocacyingreenwich.org.uk</a>	They provide one to one advocacy, training, volunteering and paid work opportunities and networking opportunities. They also support the London Forum for People with a learning disability and facilitate quarterly meetings for self-advocates from across London. The chair of the London Forum is a self-advocate, Robert, who also sits on the London Transforming Care Board. They've also facilitated additional events on topics such as Transforming Care for self-advocates, advocates and family carers.	Support service
Autism Concern	Northampton	People with learning disabilities and/or autism.	<a href="mailto:info@autismconcern.org">info@autismconcern.org</a>	They provide support and options to people with autism to help them gain independence and control of their lives.	User led organisation
Carers Oxford	Oxfordshire	Carers who look after someone aged 18 and over.	<a href="http://carersinfocarersoxfordshire.org.uk">carersinfocarersoxfordshire.org.uk</a>	They offer information, support and advice to adults who look after someone aged 18 and over who couldn't manage without this help. Their support includes telephone and online information, outreach support service, peer support groups and training and wellbeing opportunities.	Support service

Central England People First	Central England	People with learning disabilities.	<a href="mailto:northants@peoplefirst.org.uk">northants@peoplefirst.org.uk</a>	They do research, go on campaigns, help people on a one-to-one basis, speak up at meetings, do training and get involved with organisations to make sure the things that they do are good for people with learning difficulties.	There are lots of groups that use the name people first. They do similar things but are independent from each other.
CHANGE	Nationwide	Adults and children with disabilities, including people with learning disabilities and/ or autism and their family carers, and other support organisations.	<a href="mailto:info@changepeople.org">info@changepeople.org</a>	They create opportunities for people with learning disabilities to become empowered in the community through services such as training for support organisations, printed resources, and an easy read service.	
Cheshire Autism Practical Support Ltd (Chaps)	Cheshire	Families with children or adults on the autism spectrum, whether diagnosed or not.	Main contact: <a href="mailto:support@cheshireautism.org.uk">support@cheshireautism.org.uk</a>  Other contact: Jo Garner <a href="mailto:jo@cheshireautism.org.uk">jo@cheshireautism.org.uk</a>	They provide information and link to useful services to support the families of people with autism spectrum conditions, including Asperger's Syndrome.	Registered charity
Cheshire Centre for Independent Living	Cheshire	People with a range of disabilities including physical disabilities, learning disabilities and/ or autism, and their carers and families.	<a href="mailto:Lynne.turnbull@cheshirecil.org">Lynne.turnbull@cheshirecil.org</a>	They provide support with personal budgets including payroll and supported banking, personal health budgets support, advocacy and community engagement services including the Buzz Youth Activity Group.	User led organisation



Darlington Association on Disability (Centre for Independent Living)	Darlington	People with a range of disabilities including physical disabilities, learning disabilities and/or autism, and their carers and families.	<a href="mailto:mail@darlingtondisability.org">mail@darlingtondisability.org</a>	The provide support, information and services including advocacy, a carers support service, direct payment support and a parent carer forum.	Voluntary and charitable organisation led by disabled people
DASH Disablement Association Hillingdon (K/A DASH)	London Borough of Hillingdon	People with disabilities including physical disabilities, sensory impairments, learning disabilities, mental health problems and autism.	Main contact: <a href="mailto:Info@dash.org.uk">Info@dash.org.uk</a> Other contact: Rob Burton <a href="mailto:rob@dash.org.uk">rob@dash.org.uk</a>	They provide disability advice and advocacy, including support around personal budgets, disability benefits, education and healthcare plans and disability sports.	User led organisation
Gloucestershire Lifestyles	Gloucestershire	People who are aged 18+, who have a physical or sensory disability.	<a href="mailto:office@gloslifestyles.co.uk">office@gloslifestyles.co.uk</a>	They provide support including social activities, independent living service, 'managing your money' and 'self-advocacy' support services to help disabled people live independently.	Support service
Harrow Association of Disabled People	Harrow	People with a range of disabilities including physical disabilities, learning disabilities and/or autism.	<a href="mailto:U.Raichada@HAD.org.uk">U.Raichada@HAD.org.uk</a>	They provide advocacy, direct support, employment support, training, payroll service and advice about welfare benefits. They also run the Red Brick Café and can help people access radar keys and through the transition from childhood and adulthood.	Registered charity
Inclusion East	Hertfordshire and Cambridgeshire	People who have learning disabilities, with a focus on people who have complex needs.	<a href="mailto:jo.inclusioneast@gmail.com">jo.inclusioneast@gmail.com</a>	They campaign for equality and social inclusion, and represent people with learning disabilities when important decisions are made that might affect their lives.	User and family led group

<p>Inclusion Gloucestershire (formerly Gloucestershire Voices and PING)</p>	<p>Gloucestershire</p>	<p>People with disabilities and services in the local community.</p>	<p><a href="mailto:info@inclusion-glos.org">info@inclusion-glos.org</a></p>	<p>They run local area inclusion groups to build membership and provide social and participatory opportunities for disabled people within the local community. A particular area of interest is the use of drama to raise awareness of issues that are then made into DVD's and distributed. They're also piloting drop ins that are user led sessions around enablement.</p> <p>They co-chair the Learning Disability Partnership Board; hearing issues and raising further issues through the co-chairs of the board.</p>	<p>User led organisation</p>
<p>Inclusion North</p>	<p>Yorkshire and the Humber and the North East</p>	<p>People with learning disabilities and experts by experience (i.e. expert advisors who are family members or people with learning disabilities).</p>	<p>Main contact: <a href="mailto:info@inclusionnorth.org">info@inclusionnorth.org</a></p> <p>Other contacts: <a href="mailto:Ailis@inclusionnorth.org">Ailis@inclusionnorth.org</a> <a href="mailto:Rebecca@inclusionnorth.org">Rebecca@inclusionnorth.org</a></p>		
<p>Insight Autism Consultancy</p>	<p>Staffordshire</p>	<p>People who have autism and their families, support organisations, carers and other professionals.</p>	<p><a href="mailto:machita.iac@btinternet.com">machita.iac@btinternet.com</a></p>	<p>They provide training and strategies relating to autism including Asperger Syndrome.</p>	<p>Training provider</p>

Learning Disability England	England	People with learning disabilities, families and friends, housing and care providers, commissioners, training, development and consultancy organisations, academics and professionals.	<a href="http://www.learningdisabilityengland.org.uk">www.learningdisabilityengland.org.uk</a>	They bring together national bodies, including Housing and Support Alliance and People First England to discuss and campaign for the rights of people with learning disabilities and their families and carers.	National organisation
Leeds Asperger Adults	Leeds	Adults with Asperger syndrome and other forms of high-functioning autism.	<a href="mailto:leedsaspergeradults@gmail.com">leedsaspergeradults@gmail.com</a>	They provide help and support by telephone, website and email, regular group meetings at Leeds Civic Hall, newsletters and advocacy.	Registered charity
Leeds Autism AIM	Leeds	Adults with autism in the Leeds area who receive little or no funded support.	<a href="mailto:leedsautismaim@leedsadvocacy.org.uk">leedsautismaim@leedsadvocacy.org.uk</a>	They provide advocacy, information and mentoring through drop in sessions or one to one appointments.	User led organisation
Mencap Northampton	Northampton	People who need care and support including people with learning disabilities.	<a href="mailto:muriel@northamptonmencap.org.uk">muriel@northamptonmencap.org.uk</a>	They provide advice and support including employment, housing, leisure activities, respite and shopping services.	Local user led organisation. Other areas will also have local Mencap groups.



My Life My Choice	Oxfordshire, South and Midlands	Adults and young people aged 16+ with mild, multiple and profound learning disabilities.	<a href="mailto:office@mylifemychoice.org.uk">office@mylifemychoice.org.uk</a>	They provide services including community engagement, easy read translation services, support to self-advocate, public speaking and presentation skills, quality checking, care and treatment review and support, independent travel training and expertise and peer support. They also run campaigns to promote the rights of people with learning disabilities.	User led organisation
NWTDT (North West Training and Development Team) Pathways Associates CIC	North West	Health and social care organisations who support people with learning disabilities and their families.	Lynne James-Jenkinson: <a href="mailto:lynn.james-jenkinson@pathwaysassociates.co.uk">lynn.james-jenkinson@pathwaysassociates.co.uk</a>	They provide consultancy support to improve outcomes for people with learning disabilities and their families.  They've supported over 600 CTRs since 2014 and work closely with North West health and social care commissioners and specialised commissioning.	Consultancy service

Skills for People	North East Training national	Adults and children with disabilities, including people with learning disabilities and/ or autism and their family carers. They also work with support organisations and their staff.	<a href="mailto:information@skillsforpeople.org.uk">information@skillsforpeople.org.uk</a>	They support disabled people and their families and can help with independent support, personal budgets and accessible information. They also work with support organisations to deliver training and work in schools. Some of their team are involved either supporting people at the Confirm and Challenge Group, or on work streams. They were also commissioned to make an awareness raising film and to facilitate sessions for people with learning disabilities and/or autism to raise awareness about Transforming Care.	User led organisation
Speakup Self Advocacy	Rotherham	People with learning disabilities and/or autism who are lonely or isolated.	<a href="mailto:Annie@speakup.org.uk">Annie@speakup.org.uk</a>	They provide information, training and advocacy, and also host a regional forum, tackle hate crime, run People Parliament and Speakup for Autism.	User led organisation
Spectrum Northants Ltd	Northampton	People with learning disabilities and mental health problems.	<a href="mailto:info@spectrumnorthants.co.uk">info@spectrumnorthants.co.uk</a>	They provide recovery based services to help people with learning disabilities increase their self-esteem, confidence and employability, including education, work skills training, life skills training and social activities.	Employability support

Sunderland People First	North East England	People with disabilities and autism and partner organisations.	<a href="mailto:info@sunderlandpeoplefirst.com">info@sunderlandpeoplefirst.com</a>	They campaign to improve the lives of people with learning disabilities. Their advocates attend care and treatment reviews, confirm and challenge 'expert by experience', attend North East and Cumbria Transformation Board meetings and advise on national policy refresh re: care and treatment reviews.	Self-advocacy group
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