



A review of advocacy

for people with a learning disability and autistic people who are inpatients in mental health, learning disability or autism specialist hospitals

Appendix 1: About the partner organisations and reviewers

This report was written by **Kate Mercer**, NDTi Advocacy Associate, and **Gail Petty**, NDTi Advocacy Programme Lead, with support and contributions from the following individuals and organisations.



Bringing Us Together

Bringing Us Together (BUT) is a user led organisation that brings together parent carers, family members and disabled people.

For eight years BUT has:

- Supported families with lived experience of having a loved one who has been admitted as an inpatient in a mental health unit.
- Been part of national campaigns.
- Brought families together to amplify their voices.

BUT runs regular workshops with a focus on social care, wellbeing and avoiding crisis. Each includes speakers with experience of the complexities of our current services. BUT works in coproduction with families, commissioners and professionals and has carried out many rapid consultation focus groups.

Bringing Us Together team members

The following team members were directly involved in the review team:

Katie Clarke: Cofounder of Bringing Us Together has worked for over 25 years in parent participation across the country. Parent carer and foster parent.

Tony Bamforth: Workshop and course designer, writer and facilitator, wellbeing oriented, worked with disabled people and families for over 20 years across the UK.

Hazel Griffiths: Retired nurse, mum of two, parent carer for an older autistic son. Peer advocate. Campaigner and advisor and involved in many pieces of work promoting the rights and needs of families with children and young people with a wide range of disabilities.

Nicola Bartziz: A parent carer whose autistic son with learning disabilities has been an inpatient in two ATUs. He is currently thriving in supported living and Nicola is working full time in statutory advocacy.

BUT would like to thank:

- All those who attended their focus groups.
- Their steering group: Hannah Otoo, Nikki Clarke, Anya Macdonald, Jayne Knight and Sam Sly.

The Challenging Behaviour Foundation (CBF) is the only UK charity specifically focusses on challenging behaviour associated with severe learning disabilities.

The team aims to make a real difference to the lives of children, young people, and adults with severe learning disabilities and those who care for and support them. Their overarching objective is to ensure children, young people and adults with severe learning disabilities, and their families have access to the right support in the right place at the right time to enable them to live a full, healthy, and active life. They do this by combining the direct lived experience of the families we support with strategic influencing work.

Challenging Behaviour Foundation team members:

CEO Vivien Cooper (OBE) and Adult Policy Lead, Coral Histed are supported by interns Connie Mottram, Indigo Starkey, Celine Boreland and Liam Doherty. They worked in partnership with family carer Julie Thorpe to lead the review of advocacy experiences of family carers whose adult relatives are in inpatient units. Grateful thanks go to all the family carers who contributed their experiences, knowledge and recommendations for change to this project.

In addition, we would like to thank the following advisory group members for their significant input and work throughout the project.

- Yvonne Newbold (Newbold Hope, family carer)
- Bella Travis (Mencap)
- Tim Nicholls (National Autistic Society)
- Lynn James-Jenkinson (NWTDT & CEX, family carer)
- Julie Thorpe (a2e Advocacy, family carer)
- Samantha Clarke (Learning Disability England)
- Xanten Brooker (Kent County Council)



National Development Team for Inclusion

NDTi has worked with communities, government, health and social care professionals for 25 years to ensure that people with disabilities of all ages are given choice and control over their own lives.

NDTi exists to make change happen by celebrating what's possible, supporting changemakers and building self-determination. Their work always focuses on wider life outcomes with the aim to enable disabled and older people to enjoy the same opportunities as everyone else – education, paid work, a place of their own, fulfilling personal relationships and a chance to contribute to their communities.

The team believes that all people should have choice and control over their own lives, that their human rights be respected and that they are valued as equals.

NDTi team members

Gail Petty: Gail has led the Advocacy Programme and managed the Advocacy QPM at NDTi since 2015. She has

been involved in the advocacy community since 1993 and was an advocate for people with a learning disability and autistic people, including people who were inpatients.

Dr. Karen McInnes: Karen is the Evaluation Manager at NDTi. She is an experienced educator and researcher.

Kate Mercer: Kate supports advocates by delivering training, the advocacy qualification, learning events and an annual conference to the advocacy community. Kate has been an advocate for children and young people, adults and family members.

Dr. Naomi Harflett: Naomi is NDTi's Research Manager. She works on and manages a variety of research and evaluation projects across all of our work programmes.

People First Independent Advocacy

People First is an independent customer-led organisation that has worked in the North of England for over 30 years. They have a deep understanding of the region, its communities and the unique challenges.

People First is the largest provider of advocacy in Cumbria, supporting thousands of people every year to have their voices heard and helping them to live their best lives. It's an independent organisation which dedicates itself to representing people's views.

In 2009 People First helped to set up a self-advocacy network across Cumbria which created a single voice in the form of People First.

People First team members

Lindsay Graham: Lindsay is passionate about equality, respect, kindness and compassion. She is an experienced independent advocate and manages People First's advocacy offer.

Rohss Chapman: Rohss is an allie in the self-advocacy movement; committed to challenging inequality and upholding peoples' rights. She supports experts by lived experience.

Mary Docton: Mary is passionate about having equal opportunity and giving the best life for all disabled people so that they get treated equally. She is the sessional self-advocate expert by experience that is autistic.

Maria Lord: Maria works for People First on a sessional basis. She has collected information from self-advocacy organisations throughout the country and has been thoroughly inspired by their passion and dedication towards equal rights and respect for all.

Lou Townson: Lou has been part of People First for 30 years. She has a learning difficulty and is determined to ensure everybody's voices are heard in equal measure.

Lucy Irid: Lucy provides admin support at People First and has been involved in collecting and summarising information from Self Advocacy groups.



Speakup Self Advocacy

Speakup is a self-advocacy group run by and for people with learning disabilities and autistic people. The group helps people have a voice, employment opportunities and be valued and included in society.

Speakup has been supporting, employing and training people with learning disabilities and autistic people to use their skills and abilities to help others and make a difference for over 30 years.

Speakup sees people and not labels and believe that everyone has the right to live a full and enjoyable life. It all started back in 1988 when a group of people with learning disabilities came together because they were unhappy that people were not listening to them.

Speakup team members

Amy Telford: Amy is autistic, has been an inpatient herself for many years in the past, now lives independently and campaigns for the rights of autistic people.

Marshall Wilson: Marshall is autistic, has a lot of life experience as an inpatient and works as an expert by experience for Speakup.

Vicky Farnsworth: Vicky works for Speakup and has been an expert by experience on many Care and Treatment Review panels as she has a learning disability.

Geoff: Geoff supports the work of Amy, Marshall and Vicky to help deliver the project and organise the focus groups.