

# RIGHTFUL LIVES

WWW.RIGHTFULLIVES.NET

Rebecca Hilsenrath

CEO

Equality and Human Rights Commission

Arndale House

The Arndale Centre

Manchester

M4 3AQ

CC. Rt Hon Harriet Harman QC MP, Chair of the Joint Committee on Human Rights

11th October 2018,

Dear Rebecca,

We the undersigned are writing to the Equality and Human Rights Commission to outline our continued concern over the rights abuses of people with learning disabilities and/or autism who are living in inpatient units. We call on the Commission to use its statutory powers to gather evidence about the system of inpatient care for people with learning disabilities and autism in England. In 2011, A BBC Panorama documentary exposed the persistent abuse of inpatients with learning disabilities and autism at the private Assessment and Treatment Unit Winterbourne View, leading to public outrage and resulting in several criminal prosecutions. Since the Winterbourne View abuse scandal, successive governments have committed to moving people with learning disabilities and autism out of inpatient care and into community-based support. In response to this scandal, NHS England initiated the Transforming Care Programme, with the aim of transforming service provision for people with learning disabilities and autism by April 2019. At present, NHS England remains committed to closing 900 learning disability inpatient beds and reducing the number of inpatients by 35% by the end of March 2019. However, many in the sector are doubtful that these targets will be met and concerns have been raised that a rush to try and deliver on these aims will see people hastily moved out of hospital into inappropriate support.

We are concerned that the rights of many people with learning disabilities and autism living in inpatient units are not being upheld:

1. People with learning disabilities and autism are detained in hospital when they could and should be living with support in the community, due to a lack of appropriate community based support provision and wrap around provision, such as housing.

2. People living in inpatient settings are experiencing abuse, maltreatment and neglect. This includes rising levels of restraint (both physical and chemical) and the use of seclusion.
3. People living in inpatient units have limited opportunities for self-expression or to pursue personal interests.
4. People are being placed in hospital long distances from their friends, family and local community.

On 2 October 2018, BBC Radio 4's File on Four programme aired an episode on Transforming Care. This included Bethany's story. Bethany is a young woman living in seclusion in St Andrew's hospital. Bethany is fed through a metal hatch and is clinically obese, developing diabetes whilst in hospital. Bethany had parts of a biro pen stuck in her – 3 months ago she self-harmed with the pen and the hospital had not removed the pen from her arm until there was a public outcry because they deemed it is too dangerous for staff to enter her seclusion room to remove it. Bethany remains under these conditions in St Andrew's hospital, despite the fact that her psychiatrist believes she could live in the community with appropriate support. Bethany's story is just one that underlines the woeful failings in inpatient care provision for people with learning disabilities and autism and wider failings in commissioning appropriate support to live independently in the community.

The most recent figures on the demographics of people with learning disabilities and autism in hospital indicate that:

- 2,375 people were in inpatient settings
- 1,390 (59%) had been in hospital for over 2 years

Data is not available on distance travelled in the most recent figures, but the previous data set cited that 41% of inpatients travelled over 50km to their placement.

We contend that there are serious issues in service provision within inpatient settings, as well as in commissioning to move people into community-based support, which are permitting regular violations of people's rights under the Equality Act 2010 and Human Rights Act 1998.

We ask the Equality and Human Rights Commission to use its statutory powers to open an inquiry into the system of inpatient care for people with learning disabilities and autism in England, including the role of individual providers, clinical commissioning groups, local authorities and NHS England. We believe evidence-gathering is urgently needed to understand the extent of rights abuses within this system and to determine whether responsible bodies are meeting their obligations in relation to the Transforming Care Programme.

We anticipate that the Commission would be in a position to undertake further action against NHS England in failing to deliver on the Transforming Care commitments by April 2019.

We the undersigned are made up of families with experience of the system of inpatient care for people with learning disabilities and autism, as well as campaigners, academics, social enterprises and charities who wish to see greater transparency and accountability within the system. We will be pleased to work with the Commission to support any action it should choose to take in relation to the concerns we have outlined.

Yours faithfully,

Rightful Lives (campaign to highlight the human rights of people with learning disabilities)

[julienewcombe@rightfullives.net](mailto:julienewcombe@rightfullives.net)

[www.rightfullives.net](http://www.rightfullives.net)

and the following organisations;

1st Enable

Aldingbourne Trust

Appleman Legal

Article 39

Association for Real Change

Autism Rights Group Highland

Beyond Limits

Bright Futures School

Bringing Us Together

BSOP

Care Management

Certitude

Challenging Behaviour Foundation

C-Change Scotland

CHANGE

Choice Support

Citizens Advice Sheffield

Clear Autism

Dimensions

Disability Rights UK

Dudley Voices for Choice

Enough is Enough

Foundation for People with Learning Disabilities

Future Directions

Grapevine  
Heart into Help  
Hft  
IBK Initiatives  
I'm Out of Here  
In Control  
Independent Advocacy  
INQUEST  
JK Training  
Learning Disability England  
Lets for Life  
Lewisham Nexus Services  
Lewisham People's Parliament Representatives  
Ling Trust  
Lives Unlimited  
Macintyre Charity  
Mencap  
Mental Health Resistance Network  
My Great Life CIC  
My Life, My Choice  
National Autistic Society  
National Development Team for Inclusion (NDTI)  
Oxfordshire Family Support Network  
Paradigm  
Real Life Options  
Respond  
Seeability  
SEND National Crisis March  
Shared Lives Plus  
Solihull Action Through Advocacy  
Speak Up Rotherham

Summit Services

Three Cs

Together All are Able

Triangle

Voluntary Organisations Disability Group (VODG)

Voyage Care

Yarrow

The people, families and supporters who have experienced the ATU system, and those families who are not named because they have been restricted by a court from speaking publicly about their relative's situation;

Adam Knowles

Adriane Campbell

Aidan Perry

Aideen Jones OBE

Aisling Duffy, CEO Certitude

Alanna Saudade

Alex Evans

Alex Newcombe

Alexandra Gbedemah

Alicia Wood

Alison Dugmore

Ann Earley

Anne Davies

Annie Fergusson

Anthony Monaghan

Aodhan O'Cuana

AsifAMHP

Ben Glass, psychiatric survivor

Beryl Newcombe

Beth Lycett

Beth Morrison

Bethany's Dad  
Beverly Dawkins  
Brenda Fissendan  
Bryan Benetton  
Carole Mathurin  
Caroline Hunter  
Caroline Kick  
Cathy Wicks  
Cheryl Anderson  
Chris Hebden MBE  
Chris Mc Carrick  
Christian Campbell  
Christian Raphael MBE  
Christine Papalabropoulos  
Christine Stringer  
Claire Hall  
Claire Ryan  
Clare Roberts  
Clare Skidmore  
Clare Wightman, CEO Grapevine  
Courtney Evans  
Dale Kelso  
Daniel Marsden  
Danuta Gillespie  
Darren Ashman  
David Newcombe  
Deanne Shaw  
Deb Aspland  
Deb Evans  
Debbie Robinson  
Debra Oliveri

Denise Needleman

Doreen Kelly

Dr Angharad Beckett University of Leeds

Dr Christiane Pollock

Dr Damian Milton

Dr David Newman, Clinical Director Learning Disabilities Sheffield Health and Social Care NHS  
FT

Dr Jane Dalrymple

Dr Lucy Burke

Dr Lucy Series, School of Law and Politics, Cardiff University

Dr Lynn Brady

Dr Melanie Bruce

Dr Noelle Blackman

Dr Pippa Murray

Dr Sam Smith

Dr Sara Ryan

Dudley Rickard

Dunstan Rickard

Ed Parker

Eddie Parker

Eden Norris

Errol Kerr

Elaine Clarke

Ellie Mole

Elizabeth McGlone

Emma Dalrymple

Emma James-Jenkinson

Emma Keyworth

Emily Tippins

Ellie Sibbald-Perkins

Eve Whiteman

Fiona Taylor  
Fleur Bressat  
Frances Steepe  
Gail Hanrahan  
Gareth Mason  
Gary Bourlet, Founder Learning Disability England  
Geoff Doncaster  
Gill West  
Gina Regan  
Hazel Griffiths  
Helen Ashby  
Helen Cherry  
Helen Meneghello  
Henry Iles  
Ian Jones  
Ian Kick  
Ian Penfold  
Isabelle Garnett  
Isobel Cuthbertson Hall Smith  
Jackie Cookson  
Jackie Stillman  
Jade Leanne Homer  
James O'Rourke  
Jamie Andrade- Martinez  
Jamie Newcombe  
Jamie Peate  
Jan Walmsley  
Jane Crittenden  
Janet Seamer  
Janice Mclaughlin  
Janis Griffiths



Jayne Keary

Jayne Knight

Jayne Moore

Jennie Sibbald

Jenny Morris

Jenny Walker

Jeff Dawson

Jimmy Graham

Jo Hogg

Jo Hough

Jo Whitehead

John A D Palmer

John Anderson

John Hails

John Sibbald

Josephine Sirotkin, ESRC Doctoral Researcher, University of Leeds

Jordan Creed, Harrow Mencap

Jules Hipkiss

Julia Dawson

Julie Harris

Julie Newcombe, Co-Founder Rightfullives

Julie Stansfield, CEO In Control

Julie Tippins

Karen Kick

Karen Knowles

Kate Chate

Kate Mercer

Katie Clarke

Katrina Rose

Katy Tippins

Keith Sibbald

Kevin Hall  
Kim Motton  
Lauran Doak  
Laurie Morgen, Inside Autism/Outside the Box  
Lawraine Hails  
Lawrence Grady  
Leo Andrade  
Leslie Superson  
Linda Johnson  
Lindsey Brandon  
Linnet Macintyre  
Lisa Hopkins, CEO Seeability  
Lisa Perry  
Lisa Richardson  
Lisa Watchorn  
Lorraine Lish  
Lucy Hirst-Brown, MD Blue Giraffe Vision  
Luke Mc Carrick  
Lyn Roberts  
Lynn James-Jenkinson  
Lynne Mc Carrick  
Madeline Cooper- Ueki  
Mags Kelly  
Mandy Johnson  
Manuel Martinez  
Marianne Selby-Boothroyd  
Marion Rapson  
Mark L Brown, Co-Founder Rightfullives  
Mark Lever, CEO National Autistic Society  
Mark Neary, Co-Founder Rightfullives  
Mary Parker

Maureen West

Michelle Hickmott

Miles Lawson

Miray Kester

Narender Kaur

Neil Crowther

Neil Keyworth

Nick Perkins

Nicola Bartzis

Nicola Clark

Nigel Devine

Nina Ni

Pam Hickmott

Pam Robertson

Paul Gillespie

Paul Scarrot

Paula McGowan

Perry Collins

Peter Austin

Phil Kelly

Pippa Sibbald

Professor Chris Hatton, Lancaster University

Professor Daniel Goodley, Director of Research, The University of Sheffield

Professor David Abbott, University of Bristol

Professor Katherine Runswick- Cole, Professor of Education, The University of Sheffield

Professor Rebecca Lawthorn, Professor of Community Psychology, Manchester Metropolitan University

Professor Richard Huggins

Rachel Smith

Richard Evans

Robin Garnett

Robert Stillman  
Ronnie Treston  
Rosalind Grainger  
Rosemary Fretwell  
Rosie Graham  
Roy Hickmott  
Ruth Collier- Large  
Ruth Homer  
Sally Warren  
Sam Sly  
Samantha Clark, CEO Learning Disability England  
Sarah Burslem, CEO of Macintyre Charity  
Sarah Dawson  
Sarah Maguire  
Sarah Storer  
Scott Hastings  
Sean Kelly  
Sheila Handley  
Simon Cottingham  
Simon Cramp  
Simon Tovey  
Sophie Kick  
Stella Waterhouse  
Stephen Andrade- Martinez  
Steve Perry  
Steven Neary  
Sue Cousins  
Sue Jones  
Sue Sibbald  
Susan Llewelyn  
Susi Petherick

Terence Whitehouse

Tony Hickmott

Tracey Rogers

Vicki Raphael

Vivien Cooper OBE

Wayne Keary

Wendy Burt

Wendy Wilson

William Runswick-Cole

Zoe Gillespie

Zoe Thompson

And the following recently added signatories

Gillian Douglass

Peter Coleman

Dawn Hillery

Ian Denton

Euan Macleod

Mark Stanton, NAS Board of Trustees

Giselle Robertson

Alexander Kear

Samantha Harley-Pesce

Alison Giraud-Saunders

Anna Goldberg

Annie Bishop

Patricia O'Connor

Scott Watkin, BEM

Delia Smith, Mencap support worker

Christine Rose, Director Active Support Solutions

Kerry Gibbs

Annie Bannister

Carole Birtwhistle

Lisa Lenton

Matthew Brockett

Elizabeth Arenas Thomas

Sylvia Smith

Graham Smith

Richard Denny

Gary Cochrane

Deborah Coles, Director INQUEST

Sara Brockway

Margaret Collins

Rachel O'Brien, NUS Disabled Students Officer

Xan Brooker

James Murphy - psychiatric institution survivor

Susan Keller

Lisa Treacey

Steven Treacey

Jo Varela

Teresa Halliday

Katja Huijbers

Dr Sally Morgan

Rhidian Hughes

Gail Ranford

Keith Ranford

Laura Fitzgerald

Sophie Ranford

James Gibson

Tim George

Morna Boulbin

Robin Vacquier

Matthew Farley

Holly Chester

Katie George

cc. Elizabeth Prochaska, Legal Director, Equality and Human Rights Commission

If you would like to add your name to the list of people supporting the aims and objectives of this letter email:

[julienewcombe@rightfullives.net](mailto:julienewcombe@rightfullives.net)