Open Letter to The Rt Hon Andy Burnham MP, Prime Minister

Four years on: It's time to deliver the promise of the Down Syndrome Act

Dear Prime Minister

We write as one united voice on behalf of the Down syndrome community - including people with Down syndrome, families, self-advocates, clinicians, professionals, charities, campaign groups, and parliamentarians - who came together to support the passage of the Down Syndrome Act 2022 and worked alongside Government to help deliver its ambitions.

We welcomed former Minister Preet Kaur Gill's recent comments that she wants to hear the views of the Down syndrome community. **Our message is clear: four years after Parliament passed the Down Syndrome Act with overwhelming cross-party support, we are still waiting for the statutory guidance needed to make the Act a reality.**

Throughout this process, the All-Party Parliamentary Group on Down Syndrome, the National Down Syndrome Policy Group and our community have engaged constructively and in good faith. We have responded to calls for evidence, organised and attended engagement events and national consultations - many in partnership with the Department of Health and Social Care. We have worked closely with previous Ministers and Health Secretaries, contributed professional expertise and shared lived experience to help shape guidance that is practical, evidence-based and capable of improving lives. We have also written hundreds of communications to ensure that the voices and experiences of people with Down syndrome, their families and supporters are heard throughout this important work.

We did so because we believed the Government's commitment that the Act would deliver meaningful change.

Today, that promise remains unfulfilled.

The Down Syndrome Act was a landmark moment. Parliament recognised the longstanding inequalities, discrimination and barriers faced by people with Down syndrome across health, education, employment, housing and social care, and created a framework to ensure public authorities better understand, plan and coordinate support for people with Down syndrome. The Act is not about preferential treatment; it is about equitable access to services that meet people's specific needs.

The need for this guidance has never been greater.

In light of the Down Syndrome Act 2022, the recently published LeDeR Report - Learning from lives and deaths – people with a learning disability and autistic people, includes, for the first time, a dedicated chapter on Down syndrome, confirming what the community has known for decades: that people with Down syndrome experience significant health inequalities, even when compared with the wider population of people with learning disabilities. These inequalities include delayed diagnosis, inconsistent care, poor

coordination between services, and preventable harm. These are precisely the issues the Down Syndrome Act was intended to address.

The statutory guidance will not solve every challenge overnight, but it will provide a vital framework for improving awareness, accountability, consistency and coordination across public services. Every month of delay means people with Down syndrome continue to experience inequalities that Parliament sought to change.

We recognise the importance of producing guidance that is robust and effective, and we appreciate the work undertaken through consultation and engagement. However, after four years, the Down syndrome community deserves clarity on the next steps.

We respectfully ask: When will the final statutory guidance be published?

- **Will the Department commit to a clear timetable for publication and implementation?**
- **What work remains before publication?**
- **Will the final guidance reflect the concerns and priorities raised consistently by the All-Party Parliamentary Group on Down Syndrome, the National Down Syndrome Policy Group and the community throughout the drafting process?**

This is not simply about a document. It is about honouring the commitment made to thousands of people with Down syndrome and their families. It is about ensuring professionals and public authorities have the guidance they need to deliver better, more consistent support. It is about reducing avoidable inequalities and improving lives.

Our community has been patient. We have engaged constructively. We have shared our expertise and lived experience. Now we ask the Government to complete the work that Parliament began.

The Down Syndrome Act was passed because Parliament recognised that the status quo was unacceptable. Four years later, Parliament's commitment cannot be fully realised while the statutory guidance remains unpublished.

The former minister told us she wanted to hear our views. This is our collective message:

Please publish the Down Syndrome Act statutory guidance without further delay, ensuring that it reflects the concerns and priorities raised repeatedly by our community throughout the process.

We would greatly welcome the opportunity to meet with you to discuss this further at your earliest convenience.

Yours sincerely

The undersigned parliamentarians, organisations, advocates, and key professionals and stakeholder groups:

- **Sir Liam Fox** - Down Syndrome Act 2022 sponsor
- **Maria Caulfield** CBE
- **Dame Penny Mordaunt**
- **Rachael Ross OBE**, Draft Act Co-author, NDSPG
- **Ken Ross OBE**, Draft Act Co-author, NDSPG

- **Lord Addington**
- **Lord Alton** of Liverpool
- **Baroness Blower**
- **Baroness Campbell of Surbiton**
- **Baroness Cass**
- **Lord Clement-Jones** CBE
- **Lord Elliott** of Mickle Fell
- **Baroness Grey-Thompson**
- **Baroness Hollins**
- **Lord Kerr of Kinlochard**
- **Lord Storey**
- **Lord Shinkwin**
- **Lord Tope CBE**
- **Lord Touhig**
- **Lord Watson of Invergowrie**
- **Lord Weir of Ballyholme**
- **Lord Wigley**
- **Lord Bishop of Winchester,** Rt. Rev. Philip Mounstephen

- **Diane Abbott MP**, Hackney North and Stoke Newington
- **Paula Barker MP**, Liverpool Wavertree
- **Lee Barron MP**, Corby and East Northamptonshire
- **Dame Karen Bradley MP**, Staffordshire Moorlands
- **Ian Byrne MP**, Liverpool West Derby
- **Bambos Charalambous MP**, Southgate and Wood Green
- **Dame Caroline Dinenage DBE MP,** Gosport, Stubbington, Lee-on-the-Solent and Hill Head
- **Dr Danny Chambers MP**, Winchester
- **Tom Gordon MP**, Harrogate and Knaresborough
- **Lizzi Collinge MP**, Morcambe and Lunesdale

- **Jonathan Angus,** Trustee NDSPG
- **Fionn Crombie Angus,** Trustee NDSPG
- **Peter Bracket,** Trustee NDSPG
- **Dr Liz Corcoran,** Chair DSRF UK
- **Lucienne Davies,** Trustee NDSPG
- **Julie Duff,** Chair NDSPG
- **Nicola Enoch**, CEO, DSUK
- **Angela Emrys-Jones,** Vice-chair NDSPG
- **Florence Garrett,** Chair - National Down Syndrome Advisory Group
- **Lynn Murray,** Trustee NDSPG
- **Caroline Warren,** Trustee NDSPG

- **Bethany Asher**, Actor
- **Poppy Mae Barrett**, Actor
- **Otto Baxter,** Actor and Director, Ambassador NDSPG
- **Heidi Crowter,** Advocate
- **Tommy Jessop** Hon. DA, Author, Actor and Advocate, Ambassador NDSPG
- **Ross Laing**, Co-Founder Stand Out Socks, DS Advocate
- **Lester Magoogan**, Artist

- **All Wales People First** (united voice of self-advocacy groups and people with learning disabilities in Wales)
- **Down Syndrome Development Trust**, UK
- **Down Syndrome Education International**
- **Down's Syndrome Research Foundation**, UK
- **Down Syndrome UK** (DSUK)
- **The Lejeune Clinic**
- **National Down Syndrome Policy Group**
- **National Down Syndrome Advisory Group**
- **National Portage Association**
- **Royal College of Speech and Language Therapy (RCSLT) Down Syndrome Clinical Excellence Network**
- **Symbol Speech and Language Therapy**, UK

- **Bobby Dean MP**, Carshalton and Wallington
- **Tim Farron MP**, Westmorland and Lonsdale
- **Wera Hobhouse MP**, Bath
- **Paul Holmes MP**, Hamble Valley
- **Christine Jardine MP,** Edinburgh West
- **Kim Johnson MP,** Liverpool Riverside
- **Ruth Jones MP,** Newport West and Islwyn
- **John Lamont MP**, Berwickshire, Roxburgh & Selkirk
- **Sir Julian Lewis MP**, New Forest East
- **Kerry McCarthy MP,** Bristol East
- **Andy MacNae MP,** Rossendale and Darwen
- **Ben Maguire MP**, North Cornwall
- **Rachael Maskell MP,** York Central
- **John McDonnell MP**, Hayes and Harlington
- **Perran Moon,** Camborne and Redruth
- **Iqbal Mohamed MP**, Dewsbury and Batley
- **Yasmin Qureshi MP,** Bolton South and Walkden
- **Graham Stuart MP,** Beverley and Holderness
- **Jack Rankin MP**, Windsor
- **Bell Ribeiro-Addy MP,** Clapham and Brixton
- **Marie Rimmer CBE MP**, St. Helens South & Whiston
- **Jim Shannon MP,** Strangford
- **Cat Smith MP,** Lancaster and Wyre
- **Kirsteen Sullivan MP**, Bathgate and Linlithgow
- **Zarah Sultana MP,** Coventry South
- **Sir Desmond Swayne MP,** New Forest

- **Leela Baksi**, Senior Clinical Specialist Speech and Language Therapist, Professional Lead for Clinical Excellence, Symbol
- **Sarah Bartlett**, Integrated Health and Social Care Commissioner, Specialist Registered Neurodiversity Nurse

- **Archie's Smile,** Coventry and Warks
- **Arthur's Club**, UK
- **Black Child Down Syndrome**, UK
- **Bridges For Change CIC,** Cornwall
- **Bridget's ASL**, London
- **Bromley Down Syndrome Support Group**
- **21&Co**, Southwest, London and Surrey
- **Candles Down Syndrome Support Group,** Colchester
- **Cambridgeshire Babies and Children with Down Syndrome Support Group**
- **Central Wales DSSG**
- **ChatterTots Speech and Language,** Berks
- **Cornwall Down Syndrome Support Group**
- **Cotswold Downs Syndrome Group**
- **Don't Screen Us Out,** UK
- **Downright Excellent**, London
- **Down's Syndrome Derby**
- **Down's Syndrome Northeast**
- **Downright Perfect**, Dorset
- **Downright Special**, Hull and East Yorks
- **Down Right Worthy,** Cumbria
- **Greenwich Down Syndrome Support Group**
- **DOWNS and Special Friends**, West Yorks
- **Down Syndrome Cheshire**
- **Down Syndrome Oxfordshire CIO**
- **Northeast Lincolnshire DSSG**
- **Down Syndrome Liverpool**
- **Down's Syndrome Manchester**
- **Down Syndrome Group Northamptonshire**
- **Down Syndrome OK**, Surrey, Sussex & South London
- **Down With It**, Croydon
- **DS Achieve,** Herts
- **Dudley Voices for Choice** UK
- **East Lancashire Down Syndrome Support Group**
- **Electric Eels,** UK
- **Equally Abled**, Cornwall
- **Fionnathan Productions**

- **Dr Becky Baxter** SLT, Director Speech and Language Therapy, DSUK
- **Professor Sue Buckley OBE**, Director for Science and Research, Down Syndrome Education International
- **Dr Kelly Burgoyne**, Senior Lecturer in Psychology and Education, University of Manchester
- **Adam Dodd**, CEO The Minstead Trust, Hampshire
- **Pam Fry MBE**, Chair, National Portage Association
- **Jo Gawn**, Professional Lead for Service Development, Symbol UK Speech and Language Therapy
- **Dr Katie Greenland**, Assistant Professor International Centre for Evidence in Disability Research
- **Dr John Halsey** FRCP, Retd Consultant Rheumatologist
- **Angela Halsey** SRN, Retd Nursing Sister
- **Jane Jessop**, Founder Blue Apple Theatre and former Chair Winchester & District Mencap Society
- **Prof Monica Lakhanpaul**, Consultant Paediatrician, Nottingham University Hospital NHS Trust UCL Global Academic Advisor- India/South Asia, UCL Great Ormond Street Institute of Child Health
- **Helen Laverty MBE** – Professional Lead, Learning Disability Nursing, Assistant Professor University of Nottingham
- **Jo Lay** – Assoc. Director of Student Education - Learning Disabilities, University of Leeds
- **Dr Michelle McGowan**, St Barnabus Hospice
- **Paula McGowan OBE,** Founder of the Oliver McGowan Mandatory Training in Learning Disability and Autism
- **Gwen Moulster OBE**, Consultant Learning Disability Nurse
- **Sarah Offley**, Chief Officer, Dudley Voices for Choice, Coventry University
- **Get on Down's**, Sutton
- **Inclusively Down**, UK
- **Live!** Cheshire and Chester
- **Learn and Thrive**, Supporting Learners with DS, UK
- **Lowestoft Downs Syndrome Group**
- **Maths for Life,** UK
- **Minstead Learning Disability Trust**, Hants
- **Music Man Project Portsmouth**
- **NeutoHappiness CIC**, Cornwall
- **North Lancashire Down Syndrome Support Group**
- **Nottinghamshire Down Syndrome Support Group**
- **Pandas Tree, Black DSUK**, UK
- **Pershore & Evesham District Downs Support Group** (PEDDS)
- **PlayWise Learning** CIC
- **Portsmouth Down Syndrome Association**, Hants & South Coast
- **Positive Choices Network**
- **Project 21**, Suffolk, Essex, Cambridge
- **PSDS**, Surrey
- **Raising Twenty1**, North Hants
- **Rochdale Down Syndrome All Stars**
- **Seren Dwt**, Wales
- **Shine 21** Dorset Buddy Group
- **Shine 21,** North Yorkshire
- **Shropshire DSSG**
- **Sparkles: Supporting Children with Down syndrome**, Bucks
- **Solihull Down Syndrome Support Group**
- **Staffordshire Downs Syndrome Social Group**
- **Stage 21,** UK
- **Stand Out Socks**, UK
- **Sundowns**, Wirral
- **T-21**, Eastbourne
- **T21,** Brighton and Hove
- **TalkMoreCornwallCIC**
- **The Ups of Downs**, Warwickshire
- **Together 21,** Northern Ireland
- **Up and Downs**, Birmingham
- **Upside of Down**, London
- **UpsnDowns**, Northamptonshire

- **Dr Ella Rachamim**, Specialist Doctor, Community Paediatrics
- **Saoirse Read**, Learning Disability and Autism Consultant Nurse CMgr MCMI
- **Emma Short**, Queens Nurse, Nurse Consultant Learning Disabilities and Autism
- **Jon Sparkes OBE**, Chief Executive, Mencap
- **Professor Andre Strydom**, Director – Neurodevelopmental Conditions Clinical Trials Centre (NDC-CTC)
- **Phil Tittensor** Chairperson Epilepsy Nurses Association, Consultant Nurse and Honorary Lecturer for the University of Wolverhampton, UK.
- **Professor Maggie Woodhouse OBE**, Specialist Optometrist and senior lecturer at Cardiff University
- **Dr Shahid Zamin**, Assistant Professor of Intellectual Disabilities, University of Cambridge
- **Upwards with Downs,** Essex, Hertfordshire
- **Wouldn't Change a Thing**, UK

- **Claire Hatcher-Smith**, Author
- **Chris Read**, Musician and Producer