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**Shocking new report on children with learning disabilities: *Half aren't diagnosed in childhood; those who are won't collect their pension***

A new report published today, 5 November, by the UCL Institute of Health Equity (IHE) shows the Government's emphasis on 'fairness' and fixing a 'broken society' has failed, catastrophically, for hundreds of thousands of children with learning disabilities.

The IHE report *A fair, Supportive Society* shows the most vulnerable in society – those with learning disabilities – will die 15-20 years sooner on average than the general population – that's 1,200 people every year.

More shocking, explains the IHE's Director, Professor Sir Michael Marmot, is the fact that this difference is not an inevitable consequence of the underlying condition that led to the learning disability:

*"This is a direct result of a political choice that destines this vulnerable group to experience some of the worst of what society has to offer: low incomes, no work, poor housing, social isolation and loneliness, bullying and abuse.*

*A staggering 40% of people with learning difficulties aren't even diagnosed in childhood. This is an avoidable sign of a society failing to be fair and supportive to its most vulnerable members. We need to change this. The time to act is now."*

**Key Facts and Stats:**

- Former Prime Minister David Cameron said he was 'passionate' about ensuring children receive the best education that is right for them. The 2010 Conservative Party Manifesto stated: 'the most vulnerable children deserve the very highest quality of care'.
- Theresa May's Government has reiterated this ambition, stating it plans to make a 'step change' in the life chances of people with learning disabilities.
- A year ago the IHE sounded the alarm bell that government policy was not working. The health inequalities think-tank documented a slowing down in life expectancy and called for research into a potential link with austerity.
- This halt in the growth of life expectancy was confirmed this autumn by the Office for National Statistics. In fact ONS showed the picture is even more bleak: the growth has only halted in England; in Scotland, Wales and Northern Ireland it has decreased.

- In 2010 the IHE published a government-commissioned review of health inequalities, *Fair Society, Healthy Lives*. Its recommendations prioritised policies to allow a child to maximise his or her opportunity to lead as healthy and as long a life as biologically possible.
- Instead 18-year-olds today face the possibility of a shorter life than their parents; and 18 year olds with learning disabilities may well not live long enough to draw their pension.
- Around 40% of people with learning disabilities are not identified in childhood.
- More than 1,200 children and adults with a learning disability die prematurely every year.
- Children with learning disabilities are at increased risk of mental health conditions, including depression; half of the increased risk of mental health difficulties is attributable to poverty, poor housing, discrimination and bullying.
- Despite just 2.9% of the whole population having learning disabilities, a quarter of young people in custody have learning disabilities.

#### **Key interventions:**

Much of the government action needed to improve life expectancy for people with disabilities is likely to reduce health inequalities for everyone. Action should focus on the 'social determinants of health', particularly addressing poverty, poor housing, discrimination and bullying:

- **Improve early years experiences and parenting support** to help close relationships to be formed, reduce behavioural challenges, mental health problems and referral to high-cost institutional care.

*An integrated approach involving National Health Service England (NHSE), and Local Authorities (LAs) via Public Health England (PHE), to develop a version of Incredible Years for parents of children with learning disabilities, found a reduction in parent behaviours described as negative, from 62.8% at baseline, to 24.3% after 12 weekly sessions.*

- **Reduce poverty and improve living environments** to improve ability to choose healthy behaviours and be socially included

*Households with children who have a disability are twice as likely to be living in housing that is too cold in winter (a fifth of children with learning disabilities have asthma).*

- **Increase employment programmes** to increase life expectancy by improving mental and physical health, reduced poverty and associated health impacts – currently the number of people with learning disabilities in work, paid at minimum wage or higher, vary widely across regions of the UK from 0.3% to 22.1%

*Walgreens Pharmacy chain in the in the US, actively recruits people with learning disabilities in their distribution centres. This is a successful business decision, not a charitable venture. The company have found that people with cognitive impairments are equally productive, have less accidents, and that, depending on site, staff turnover reduced by 20-50%.*

- **Improve social integration and acceptance** to reduce bullying, increase ability to work and mental health.

*Participation with Best Buddies scheme led to increased feelings of acceptance by their friends and communities, with 55% reporting feeling more confident in engaging with other online social networks – with local authority support similar increases in participation may be achievable through, for example, inclusion in sports, commerce and public sector employment.*

## **Notes to Editors**

### **Summary of Recommendations**

Recommendation 1	NHSE, with PHE, DHSC, DWP, Association of Directors of Children’s Services (ADCS), HMT, Home Office and Other Government Departments (OGDS) and stakeholders, should develop an evidence based integrated strategy, that supports households holistically, from identification of a learning disability through to related early years support, and also onwards throughout life.
Recommendation 2	Joined up working is key. Teams from the above mentioned departments, and others in the community, should integrate to improve outcomes through action on specific social determinants of health for people with learning disabilities. For example, to reduce poverty and simultaneously improve the physical and social environment for people living in deprived areas.
Recommendation 3	Ensure no one is left out. Improve early identification rates. Rationalise information-sharing across all agencies and across registers, such as sharing all age General Practice (GP) Learning Disability registers with Las and to inform the Education, Health and Care (EHC) planning process.
Recommendation 4	DfE and Health and Social Care Commissioners should lead the change in the ‘choice architecture’ by removing unhealthy options at influential institutional settings, such as in hospitals and care settings, to support healthier behaviours for people with learning disabilities, and to support the parents of children with learning disabilities to do the same.
Recommendation 5	DfE and NHSE adopt the ‘equal right to sight’ approach and work together with charities to appropriately design eyesight and hearing tests, administered to all pupils in special and mainstream schools within their first year of joining.
Recommendation 6	DfE and NHSE formally require that actions are integrated into the Education and Health Care plan from the beginning, to ensure improved take-up of: appropriate-to-age screening tests, improvements in health behaviours, and improved action on the social determinants of health.
Recommendation 7	DWP and DHSC, with the Joint Health and Work Unit (JHWU), learn from trials and existing programs, and work with LAs and employers to ensure that best practice supported employment offers are available nationally, and provide stakeholders with a timetable that delivers this as rapidly as possible.

Recommendation 8	Government, specifically DWP and DHSC, should undertake a systematic review of how it supports people with a learning disability, ensuring that access to work, homes, benefits, health and care services and education are adequate. A review of the sufficiency of the Education, Health and Care Plan's (EHCP) personal budget is advised, to identify whether or not this is being adequately rolled out to those in most need.
Recommendation 9	PHE, LAs and NHSE support coordinated campaigns for greater integration of people with learning disabilities into mainstream society, to reduce discrimination and aid familiarisation and representation. This should include a push towards more integration with mainstream schooling. To build on progress made by NHSE, public sector employers should be mandated to provide opportunities for those with learning disabilities, and private sector employers should be incentivised to do the same by supporting apprenticeships for people with a learning disability.
Recommendation 10	Launch a hearts and minds campaign, led by a collaborative of learning disability campaign groups close to the cause, to improve attitudes towards people with learning disabilities. This should build on successful campaigns for other minority groups. Alongside this, a review of general attitudes and perceived safeguarding requirements and procedures within professional, community and educational settings may be useful to understand detrimental attitudes towards people with learning disabilities. This work should be evaluated given that there is little evidence regarding effective practice in this area. Further, tougher and more visible punishment of crimes against those with learning disabilities should be considered by the Home Office.
Recommendation 11	Set up friendship support groups to be made available to all people with learning disabilities. As a part of EHC plans, children and young people with learning disabilities should be linked with friendship groups, and to networks that will support their participation in society. A wellbeing plan for adults with learning disabilities should consider not just the medical needs arising from their disability, but also their social interaction needs. Professionals should be required to link people with a learning disability with appropriate friendship support groups.

SEN	Special Educational Needs
EHC	Education, Health and Care
EHCP	Education Health and Care Plans
SSEN	Statement of Special Educational Needs
MLD	Moderate Learning Difficulties
SLD	Severe Learning Difficulties
PMLD	Profound and Multiple Learning Difficulties
NHSE	National Health Service England
PHE	Public Health England
DWP	The Department for Work and Pensions
HMP	Her Majesty's Treasury

JHWC	Joint Health and Work Unit
DHSE	Department of Health and Social Care
DfE	Department for Education
LGA	Local Government Association
ADCS	Association of Directors of Children's Services
ODGs	Other Government Departments
GP	General Practice/General Practitioner
CQC	Care Quality Commission
Ofstead	Office for Standards in Education, Children's Services and Skill
ADASS	The Association of Directors of Adult Social Services in England
QOF	Quality and Outcomes Framework
SEND	Special Educational Needs and Disability Support
CYPMHS	Children and Young People's Mental Health Services
RCTs	Randomised Control Trials
NICE	National Institute for Health and Care Excellence
UC	Universal Credit

**About the UCL Institute of Health Equity [www.instituteoftheequity.org](http://www.instituteoftheequity.org)**

Our mission is nothing less than a fairer, healthier society.

The UCL Institute of Health Equity was established in 2011 and is led by Professor Sir Michael Marmot.

The aim is to develop and support approaches to health equity and build on work that has assessed, measured and implemented approaches to tackle inequalities in health - works such as the 'WHO Commission on Social Determinants of Health' and 'Fair Society Healthy Lives' (The Marmot Review).

Since 2011, the Institute has led and collaborated on works to address the Social Determinants of Health and improve health equity.

These works include the PAHO Commission on Equity and Health Inequalities in the Americas, a Review of Social Determinants of Health and the Health Divide for the WHO European Region, Indicators for Local Authorities in England, Healthy Places, Healthy Lives, Social Determinants of Mental Health, local practice resources for public health.