INSTITUTE *of* HEALTH EQUITY

A fair, supportive society

Summary report

A social determinants of health approach to improving the lives and health of people with learning disabilities.

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ABOUT THIS PRACTICE RESOURCE

This practice resource was written for the National Health Service England (NHSE) by Dr Angela Donkin and Dr Wendy Rickard of the UCL Institute of Health Equity. The authors are grateful to NHSE and to all of those who contributed and commented on the report through consultation.

About the UCL Institute of Health Equity

The UCL Institute of Health Equity (IHE) is led by Professor Sir Michael Marmot and seeks to increase health equity through action on the social determinants of health, specifically in four areas: influencing global, national and local policies; advising on and learning from practice; building the evidence base; and capacity building. The Institute builds on previous work to tackle inequalities in health led by Professor Sir Michael Marmot and his team, including the Commission on Social Determinants of Health, Fair Society Healthy Lives (The Marmot Review) and the Review of Social Determinants of Health and the Health Divide for the WHO European Region.

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FOREWORD

Fair Society, Healthy Lives, the Marmot Review (2010), set out the reasons for socioeconomic inequalities in health and what could be done to reduce them. That review did not look at specific high-risk groups. This new report extends that analysis to focus on inequalities in health and the drivers of health for people with learning disabilities in England.

A shocking finding is that people with learning disabilities die 15 to 20 years sooner on average than the general population. Were this an inevitable consequence of the underlying condition that led to the learning disability, it would be sad but not so much a matter of social justice. But that is not what is shown by the evidence brought together in this report. People with learning disabilities are more likely than the general population 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. Quite simply, this is a sign of a society failing to be fair and supportive to its most vulnerable members.

We need to change this.

The Institute of Health Equity has for a long time been helping to disseminate best practice, to help practitioners and policy-makers to improve the social determinants of health. This report is in that tradition. It provides encouragement by showing that programmes and opportunities exist to improve outcomes for people with learning disabilities. I hope that the evidence presented will inform the Government's stated ambition to make a 'step change' in the life chances of people with learning disabilities.

Much of the action to improve the social determinants of health for those with learning disabilities will also improve health for others at higher risk of ill health because of social disadvantage. Therefore the actions recommended here will not only improve lives and health outcomes for a highly vulnerable group, people with learning disabilities, but could also help to reduce inequalities in health across the population. The time to act is now.

Professor Sir Michael Marmot
Director of the UCL Institute of Health Equity

LIST OF ABBREVIATIONS

ADASS	The Association of Directors of Adult Social Services in England
ADCS	Association of Directors of Children's Services
CQC	Care Quality Commission
CYPMHS	Children and Young People's Mental Health Services
DfE	Department for Education
DHSC	Department of Health and Social Care
DWP	The Department for Work and Pensions
EHCP	Education, Health and Care Plans
GP	General Practice / General Practitioner
HMT	Her Majesty's Treasury
JHWU	Joint Health and Work Unit
LGA	Local Government Association
MLD	Moderate Learning Difficulties
NHSE	National Health Service England
NICE	National Institute for Health and Care Excellence
Ofsted	Office for Standards in Education, Children's Services and Skills
OGDs	Other Government Departments
PHE	Public Health England
PMLD	Profound and Multiple Learning Difficulties
QOF	Quality and Outcomes Framework
RCTs	Randomised Control Trials
SEN	Special Educational Needs
SEND	Special Educational Needs and Disability Support
SLD	Severe Learning Difficulties
SSEN	Statement of Special Educational Needs
UC	Universal Credit
UCL IHE	University College London Institute of Health Equity

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EXECUTIVE SUMMARY

- This report by the UCL Institute for Health Equity (UCL IHE), the authors of *Fair Society, Healthy Lives:* The Marmot Review (1), considers the value of applying a social determinants approach to improve the lives and health outcomes of people with learning disabilities.

- People with learning disabilities die, on average, 15 to 20 years sooner than people in the general population. It is estimated that more than 1,200 children and adults with a learning disability die prematurely every year. (361) (362) (185) Many of the early deaths of people with learning disabilities could be reduced through improved healthcare and preventative actions.

- While learning disabilities may have a biological basis, other factors, aside from health care provision, can impact on health, wellbeing and premature mortality for people with learning disabilities. The social determinants of health have been identified as the main factors influencing health alongside genetics, and health care provision. (1)

- Children with learning disabilities are generally more likely to have mental health conditions, including depression. Over a third of children with learning disabilities have psychiatric disorders, one fifth have behavioural problems, and one fifth have emotional issues. Evidence shows that nearly half of the increased risk of mental health difficulties among children with a learning disability may be attributable to their increased rate of exposure to the common social determinants of poorer mental health – poverty, poor housing, discrimination and bullying – rather than to the disability itself. (31, 32)

- Given the importance of social determinants in influencing health and wellbeing, if we are to improve health outcomes it is especially important to address the social determinants of health for this population, who experience worse social determinants than average.

This report finds that, compared to the general population, people with learning disabilities are:

- More likely to be subject to pressured parenting environments, and have more difficulty forming close relationships in their early years, which can, for example, lead to behavioural and mental health problems. (16)

- More likely to live in poverty, which can limit the ability and freedom to purchase healthy options, be socially included, and/or afford decent housing. Data from 2000–2015 on material inequalities illustrates that the percentage of pupils at state-funded schools eligible for free school meals dropped during this time. However, the percentage of children with special educational needs (SEN) associated with learning disabilities who had a statement or education, health and care plan (EHCP) who were eligible for free school meals rose in all groups, from 36.0% to 37.8% for children with moderate learning difficulties (MLD), from 32.9% to 35.5% for children with severe learning difficulties (SLD) and from 25.4% to 29.0% for children with profound and multiple learning difficulties (PMLD). (34)

- Less likely to be in work. There is a lack of data on the proportion of all adults with a learning disability who are employed in England, but past studies have suggested that about 17% of all working age people with a learning disability have a paid job. (364) Only 5.7% of people with a learning disability who are known to their local authority have paid work. (200) This is highly significant because unemployment has been associated with increased premature mortality and poor mental and physical health as well as increased poverty and associated health impacts.

- More likely to live in poor environments. Compared with families who are not supporting a child with a disability, households with children who are disabled had a 50% increased risk of having damp in the children's bedroom and were twice as likely to be in housing that is too cold in the winter. (9, p8) This is very likely to have a detrimental impact on health. A fifth of children with learning disabilities have asthma and a third wheezing.

- More likely to be bullied and discriminated against, which can negatively impact on social integration, ability to work and mental health. (253, 254, 255, 256)

- More likely to live socially isolated, lonely lives. Fifty per cent of people with a learning disability experience chronic loneliness, compared with around 15–30% of people in the general population. (307) Loneliness is associated with depression and stress, high blood pressure and higher mortality risk. (307, 308, 309, 310, 311) The magnitude of the effect of loneliness is comparable to smoking, and the impact is greater than that of many well-known mortality risk factors, such as obesity and physical inactivity. (311)

  Given that people with strong and developed social relationships may have a 50% less risk of mortality compared with people with less developed social relationships, loneliness among people with learning disabilities strongly relates to inequities in health outcomes for people with learning disabilities. This problem responds well to intervention as programmes to reduce loneliness have positive impacts.

- The evidence clearly suggests that, as a society, we are not supporting this vulnerable group as well as we should.

- Improving the daily lives of people with learning disabilities will carry costs: to set up employment programmes, to ensure adequate incomes, to improve housing, and to deliver parenting support, for instance. However, it is important to note that there will also be positive returns on this investment. For example:

  - Despite just 2.9% of the whole population having learning disabilities, a quarter of young people in custody have learning disabilities. (61)

  - Interventions to provide early years experiences that feature positive attention to the child, and improved parenting support, should,

the evidence suggests, contribute to both a reduction in challenging behaviour among young people, and a reduction in the numbers of people in high-cost institutional care.

- As an example of a successful intervention in the form of a business decision, Walgreens Pharmacy chain in the United States actively recruits people with learning disabilities in their distribution centres. The company has found that people with cognitive impairments are equally productive, have less accidents, and that, depending on the site, staff turnover reduced by 20–50% as a result of this recruitment policy. (350)

Rolling out best practice.

The report provides some examples of effective systems and interventions to illustrate that action can be effective. The existence of better outcomes is encouraging and it is clear that best practice should be rolled out more widely to achieve the following:

- **An improvement in early years experiences.** An integrated approach involving National Health Service England (NHSE) and local authorities 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. (70)

- **A reduction in poverty.** Following the Swedish model for social welfare, reform through combined efforts by the Department for Work and Pensions (DWP) and Her Majesty's Treasury (HMT) would, if as effective in the UK as in Sweden, eliminate money worries for this group. (46)

- **An increase in the percentage in work.** Following the Vermont supported employment scheme example, which works to improve employment

opportunities and outcomes for people with disabilities, the Joint Health and Work Unit (JHWU), through the DWP and the Department of Health and Social Care (DHSC) in the UK, could potentially increase the percentage of people with learning disabilities in work to 48%, paid at minimum wage or higher. (152) The percentages of people with a disability in work in the UK vary by region, from 0.3% to 22.1%. At the least, a target to reach the same level as the best performing regions is warranted.

- **Improved social integration and acceptance.** After participation with the Best Buddies scheme, which works to end social, physical and economic isolation of people with learning disabilities, three-quarters of people with learning disabilities in a 2014 survey reported feeling more accepted by their friends and in their communities, and 55% reported feeling more confident in engaging with online social networks. With support from local authorities, similar increases in participation may be achievable, for example through inclusion in sports, commerce and public sector employment. (327)

- To ensure everyone gets the support needed, identification and registration of learning disabilities needs to be improved, at present approximately 40% of people with learning disabilities are not identified in childhood. (23)

- In general, to conclude, the review finds that the recommendations made in the Marmot review (1) are equally, if not more important for this particularly excluded group. In addition there are some specific tailored recommendations that address particular issues that are unique to people with learning disabilities. The recommendations are summarised in the next pages.

SUMMARY OF RECOMMENDATIONS

Recommendation 1

NHSE, with PHE, DHSC, DWP, the Association of Directors of Children's Services (ADCS), HMT, the 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

To ensure no one is left out, early identification rates should be improved and information-sharing rationalised across all agencies and across registers, such as sharing all age General Practice (GP) Learning Disability registers with local authorities and to inform the education, health and care (EHC) plan 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 should adopt the 'equal right to sight' approach and work together with charities to appropriately design eyesight and hearing tests, administered to all children in special and mainstream schools within their first year of joining.

Recommendation 6

The DfE and NHSE should formally require that specific actions are included in the education, health and care plan process 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), should learn from trials and existing programmes, and work with local authorities and employers to ensure that employment offers for people with learning disabilities are available nationally, and provide stakeholders with a timetable that delivers this as rapidly as possible.

Recommendation 8

The Government, specifically DWP and DHSC, should undertake a systematic review of how it supports people with learning disabilities, ensuring that access to work, homes, benefits, health and care services and education are adequate. A review of the sufficiency of the personal budget for EHC plans is advised, to identify whether or not this is being adequately rolled out to those in most need.

Recommendation 9

PHE, local authorities and NHSE should support coordinated campaigns for greater integration of people with learning disabilities into mainstream society, to reduce discrimination and stigma and support representation. This should include a push towards more inclusion of children with learning disabilities within 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 learning disabilities.

Recommendation 10

A hearts and minds campaign is recommended, led by a collaboration 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

Friendship support groups should 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.

1. INTRODUCTION

The Institute for Health Equity (IHE) at University College London has been supported by the National Health Service England (NHSE) to consider the value of applying a social determinants approach to identify opportunities to improve the lives and outcomes of people with learning disabilities.

1.1. THE SOCIAL DETERMINANTS OF HEALTH

A learning disability may be biologically driven. However, health and wellbeing are determined not just by biology but by a combination of social, behavioural and genetic and biological factors. (26, p10) These factors can operate in isolation or in combination, either to protect health or cause a decline in health outcomes. For people with learning disabilities, as for the rest of the population, their health and wellbeing outcomes will be maximised when social conditions are favourable.

This review and think piece focuses not on biology and medical care but on the opportunities available to boost health and wellbeing through improvements in the conditions in which people are born, live and work: the social determinants of health.

In 2010, the IHE's *Fair Society, Healthy Lives*, known as The Marmot Review (1) set out the key drivers of inequalities in health outcomes. The review, after assessing the evidence, set out the following key policy recommendations on the social determinants of health throughout the life course:

1) Give every child the best start in life

2) Enable all children, young people and adults to maximise their capabilities and have control over their lives

3) Create fair employment and good work for all

4) Ensure a healthy standard of living for all

5) Create and develop healthy and sustainable places and communities

6) Strengthen the role and impact of ill-health prevention

Inequalities in how society treats and values people, and the perceived status that people have, influence physical and mental health. Efforts to reduce structural barriers that cause discrimination and negative impacts on lives should therefore be a priority concern for government policy. A well governed and compassionate society values and supports all its citizens.

1.2. AIMS AND SCOPE OF THIS REPORT

This report summarises the main themes for people with learning disabilities, following a life course approach and covering the key Marmot Review (1) social determinant areas.

The report is not based on a systematic review, but rather a comprehensive review of major reports and research findings available both from the academic and policy literature. In addition to reviewing the importance of social determinants, we also searched for examples of effective interventions to illustrate actions that could improve outcomes. Therefore, the reference list at the end of this document includes both cited documents and uncited further reading.

From the review we found that outcomes for people with learning disabilities are often not reported, definitions utilised vary considerably, international comparisons are difficult, and many interventions have not been evaluated. However, the work summarised here provides a clear rationale for further investigation and also for action to improve the lives of people with learning disabilities in a number of areas.

People with learning disabilities die, on average, 15 to 20 years sooner than people in the general population and many of those deaths could be avoided through improved healthcare and preventative actions. It is estimated that more than 1,200 children and adults with a learning disability die prematurely every year. (361) (362) (185)

2. EARLY YEARS

The Marmot Review showed for all children in the early years:

- What happens during the early years has lifelong effects on many aspects of health and wellbeing.

- Having a low income, and particularly being in debt, can negatively impact on children's health and wellbeing.

- There are effective programmes to support children and their parents in the early years.

- The earlier support can be actioned, the better children's outcomes.

2.1 NUMBERS AND CHARACTERISTICS OF YOUNG CHILDREN WITH LEARNING DISABILITIES

- It is estimated that in the UK 2.7% of all children have learning disabilities (6) but just under 60% of these children are known to state services as they grow up, (23) and there is a high level of regional variation in recorded prevalence. (13) There are known links between ethnicity and learning disability. Pakistani ethnicity is associated with high rates of severe learning disability. (11, 13, 21) Higher rates of mild learning disabilities are noted among Gypsy, Roma and Traveller children. (21)

- The importance of improved identification rates should not be underestimated: people with learning disabilities who are not known to services in childhood are those who are more likely to be in secure settings in later life. (277)

- Between 2009/10 and 2014/15 the number of children recorded with a learning disability reduced by 6.5%, accounted for by a reduction in children recorded with mild learning disabilities. (7)

- In 2014, just over one in four looked-after children had a special educational need associated with learning disabilities. (23)

2.2 SOCIAL DETERMINANTS FOR YOUNG CHILDREN WITH LEARNING DISABILITIES

Growing up in a supportive environment provides the basis for a good start in life. While most children with learning disabilities live in supportive environments where resources are sufficient, not all do. Children living in families with low socioeconomic position have poorer mental health and display more risky health behaviours, such as sedentary lifestyles, worse diet and substance misuse (34). This applies both to children with and without learning disabilities. It is therefore a concern that children with learning disabilities are more likely to be exposed to a range of experiences that negatively impact on health and wellbeing outcomes. (34) These factors have also been demonstrated as important for contributing to health inequalities by the Marmot Review (1) and by the IHE report *An Equal Start: Improving outcomes in Children's Centres*. (183) In more detail, they include:

Pressured parenting environments and difficulty forming close relationships

Most children with a learning disability will grow up in supportive households where parents are dedicated, passionate and fight tirelessly for the needs and inclusion of their children, but added pressures on families mean that, compared with the general population, children with learning disabilities are:

- less likely to have a close relationship with their mother

> *Children with learning disabilities are more likely to live in households with poor social determinants, e.g. poorer early years experiences, low incomes and overcrowded and cold housing. (34)*

> *These risk factors are contributing to the higher rates of respiratory conditions, obesity and poor mental health seen in this group. (9)*

- more likely to be exposed to chaotic family and parenting environments and family instability
- more likely to be vulnerable to neglect, physical, sexual, emotional abuse and violence

Increased exposure to negative environmental factors

Compared with the general population, children with learning disabilities are:

- more likely to be exposed to tobacco smoke (34, 183)
- more likely to live in housing that is rented, overcrowded, in a poor state of repair and too cold in winter. (34, 183)

Discrimination and violence

Compared with the general population, children with learning disabilities are:

- more likely to be exposed to violence (34)
- more likely to be bullied (34)

Economic disadvantage

Compared with the general population, children with learning disabilities are:

- more likely to live in poorer households and be eligible for free school meals (34)
- less likely to live in families that have access to resources such as wealth and power (34)

Insufficient access to health services

Compared with the general population, children with learning disabilities are:

- less likely to access timely, effective and appropriate healthcare including health prevention and promotion activities (34)

Children with learning disabilities are generally more likely to have mental health conditions, including depression: over a third of children with learning disabilities have psychiatric disorders (26), a fifth have behavioural problems and a fifth have emotional issues (9). Evidence shows that nearly half of the increased risk of mental health difficulties among children with learning disability may be attributable to their increased rate of exposure to common social determinants of poorer mental health – poverty, poor housing, discrimination and bullying – rather than to the learning disability itself (13, 31, 32).

Many of the determinants identified above are modifiable risk factors. We know, for instance, that: effective interventions support and improve bonding and parenting; effective programmes to reduce domestic violence exist; housing quality can be improved; social networks and support for parents in similar positions can be set up, and families can be given more resources to help them cope. (65, 66, 68, 70, 71, 173, 174)

2.3 WHAT WORKS TO IMPROVE OUTCOMES

EARLY INDENTIFICATION AND INTERVENTION

Given that only an estimated 60% of children with learning disabilities are known to state services as they grow up, (23) improvements in identification are needed. Delays in identification can lead to a lack of access to necessary services such as speech therapy. Where children are not meeting developmental milestones, parents of children with unidentified learning disabilities will not be best able to support them. (6)

'Early Identification and Intervention' was part of the National Services Framework for Children and Young People from 2004 and was enshrined in the Children and Families Act (2014). Local area inspections are conducted by the Care Quality Commission (CQC) and Ofsted. Alongside evaluating an area's effectiveness in meeting needs and improving outcomes, the inspection of the local area includes an assessment of effectiveness in identifying children and young people who have special educational needs and disabilities.

It is important to investigate the reported fall in numbers of children with mild to moderate disabilities, to ensure children are not being lost from education, health and care systems and are not excluded from help and support that might improve long-term outcomes across the life course. The reported reductions may be linked to changes in surveillance, service eligibility and stigma associated with learning disability leading to an unwillingness for parents to use specialised learning disability services. (9)

Recent work has set out the basis for good models of care for children with learning disabilities that have, or are at risk of developing, behaviours that challenge; this includes work by the Challenging Behaviour Foundation (2014), (2) the National Service Model (NHSE), the Local Government Association (LGA), ADASS (the Association of Directors of Adult Social Services in England) (2015), (74) and the Lenehan Report (2017) (61). These initiatives and reports recommend early identification and intervention.

Clearly, more needs to be done to pick up issues earlier. For example, the Department of Health and Social Care (DHSC) development checks are an ideal opportunity to identify learning disabilities and have GPs register them. Similar actions are already incentivised in the Quality and Outcomes Framework (QOF) within the GP contract, for developing and maintaining a register of patients with learning disabilities. These checks should identify learning disabilities and signpost households to appropriate support. However, there is some evidence to suggest that those charged with these checks may be overstretched, and coverage is not universal, and therefore we may not be properly assessing the needs of all young children. (186)

Parents should also be helped to know how to raise concerns regarding child development issues, and to be supported in doing so. Once referred, children should be assessed quickly.

An estimated 40% of children with learning disabilities are not identified by services. Clearly we need to improve identification to provide support. (23)

INFORMATION AT IDENTIFICATION

- set out additional care that the child requires, what parents can do, and what others can help with
- automatically lead to the triggering of the education, health and care plan (EHCP) process as a child is approaching school age
- reinforce the importance of maintaining basic health regimes – dental checks, eye tests, healthy food, exercise
- set out developmental milestones and reinforce the need to praise and provide warm and positive parenting and caring alongside consistent boundaries and routines
- provide access to specialist parenting training programmes where that help is indicated
- signpost parent/carer support groups
- provide parents/carers with information that can help to support their wider life – for example, regarding financial support and return to work, housing improvement officers and child or respite care provision

INCOME IMPROVEMENT AND POVERTY REDUCTION

Having a low income, and in particular being in debt, can negatively impact on children's health and wellbeing, and that of their carers. (76) Households with children who have a learning disability are more likely to have lower incomes and live in more deprived areas than those without. (34) Efforts should be made to address this, recognising the barriers to increasing household incomes in this group.

Ideally, all families would earn enough money to reach a minimum income for healthy living, as set out in the Marmot Review. (1) Once identified, children with learning disabilities living in poverty should be supported adequately.

An education, health and care plan (EHCP) is provided to all children and young people aged up to 25 who would previously have had a 'statement' of special educational need. The EHCP now includes health and care needs, and once need is stated there is a duty to deliver services to address it. The EHCP is aimed at recipients who need the most support, and is available through special educational needs and disability (SEND) support in schools. Some children given an EHCP will be provided with a personal budget to help achieve improved outcomes, but this is dependent on identification and eligibility. There needs to be a review of how sufficient this personal budget is, and whether or not this system is being adequately rolled out to those in most need.

We know that families with children with learning disabilities can struggle to find good quality childcare, and because of the long care-giving hours they are providing, carers of children with learning disabilities generally experience worse health outcomes themselves than carers of children with other challenges. This can create barriers for carers of children with learning disabilities who want to enter the labour market.

We have not found evidence of effective programmes in the UK specifically designed to raise the incomes of households containing children with learning disabilities, but consideration could be given to implementing approaches that are effective elsewhere. For example:

- We know, from work across Europe, that countries with more generous social support packages have lower levels of child poverty. (46)

- We know from IHE's previous work to identify best practice that there are a number of effective interventions to improve the social determinants of health (e.g. incomes, work quality, childhood experiences and social inclusion). (291)

IMPROVING ACCESS TO APPROPRIATE SERVICES

Once a learning disability has been identified in a child, there are a range of targeted/specialist support programmes and structural approaches that can improve the social determinants of health. As detailed in the Lenehan Report (61, p14), these include:

- access to ongoing support in community living and intensive crisis support so that help can be provided before things go wrong. These services need to be good-quality and trusted
- support for those experiencing violent relationships
- a 'Positive Behaviour Support' programme that is used at school, home and other settings
- home assessment and holistic services that support the whole family and not just the child
- strong integration and early links with education services and Children and Young People's Mental Health Services (CYPMHS)
- wrap-around multi-agency support such as EHCPs, which are a genuine vehicle for bringing 'whole child' planning together, taking a whole-life approach and focusing on what matters to the child and their family
- educational settings that understand behaviour as a form of communication and seek to fully include children as much as possible

- good therapeutic short breaks services that provide positive opportunities for young people and support to caregivers
- jointly commissioned residential services and outreach services that feature care, education and compassion
- effective in-patient units that are integrated with community support services so that there is a comprehensive support journey from community to in-patient and back out to community in a timely, effective and supportive manner
- Carers and those with learning disabilities having a good understanding of the benefits and purposes of in-patient units

EFFECTIVE PARENTING SUPPORT PROGRAMMES

There is evidence that outcomes for children with learning disabilities can improve when parent training programmes are utilised.

For example, McIntyre evaluated an adapted version of the Incredible Years programme with 2- to 5-year-olds with learning disabilities. There was a reduction in negative parent behaviours (from 62.8% of parents at baseline to 24.3% of parents after 12 weekly sessions) and in negative child behaviour (10.12% of children at baseline to 6.18% after programme). (70)

Triple P also has a specific programme, called Stepping Stones, which is designed for parents of children aged 2 to 8 with learning disabilities. Some randomised controlled trials (RCTs) have found strong evidence that Stepping Stones improves child and parent outcomes for children with learning disabilities. (68) For example, in a meta-analysis of 12 RCTs, Tellegan and Sanders reported a significant medium effect size in reducing child problems, with significant medium to large effect sizes found on parenting style, and parenting satisfaction and efficacy. (68) Significant medium effect sizes were found on parents outcomes and on parental relationships . Improvements in observed child behaviours showed significant effects. (68)

Efforts to support positive social and emotional development are crucial to improve children's ability to integrate socially, and to reduce the risk of challenging behaviours becoming problematic in youth. (59)

The Incredible Years programme with 2- to 5-year-olds with learning disabilities reported reductions in negative parent behaviour from 62.8% at baseline to 24.3% after 12 weekly sessions. (70)

2.4 THE EARLY YEARS: MOVING FORWARD

The recommendations to support early years development set out in the Marmot Review (1) are as valid for young children with learning disabilities as for the general population, and are even more critical for the former group as they are more likely to be at risk from unsupported parenting or caring practices and poor social conditions. Our key recommendations therefore reflect the importance of integrating social determinants of health into health strategies for young children with learning disabilities.

In addition, and specific to young children with learning disabilities, it is clear that more focused support is required. There are examples of effective targeted programmes for parents of young children that have been developed

Recommendation 1

NHSE, with PHE, DHSC, DWP, the Association of Directors of Children's Services (ADCS), HMT, the Home Office and Other Government Departments (OGDs) and stakeholders, should develop an evidence-based integrated strategy that supports households holistically, from identifcation of a learning disability through to related early years support, and also onwards throughout life.

Recommendation 2

Cross-departmental teams should work together to improve the social determinants of health for people with learning disabilities, for example to reduce poverty and improve the physical and social environment for those living in deprived areas. Supporting the least advantaged in society is a matter of social justice, and the primary reason for welfare benefits. Additional support is necessary, although costly. However, longer-term savings to the DHSC and other areas of national and local government are likely to result, as more support yields multiple benefits and reduces demand on a range of services. DHSC and other government departments should work closely with Her Majesty's Treasury (HMT) to support longer-term and cross-government accounting of improvements in social and environmental conditions so that savings accruing to DHSC for instance may be shared among other departments that are providing additional support. This could be helpful in prioritising more broad-ranging work to reduce demand on the National Health Service.

Recommendation 3

To ensure no one is left out, information-sharing should be rationalised across registers and through the EHCP process. Work should be joined-up among: GPs (which requires GPs to identify those with learning disabilities of all ages in their practices), schools (monitoring early-years skills at age 5 and through the EHCP process), and health visitors and childcare professionals (checking on children aged 12 and 22 months). This should significantly improve the developmental surveillance of children with learning disabilities. There could be a standard requirement stating that when a learning disability is identified or recognised as part of the EHCP process, a standard letter is sent to the child's or young person's GP, asking that the status is recorded on the medical record.

3. CHILDREN AND YOUNG PEOPLE

The Marmot Review showed for all young people:

- A vision for addressing the social determinants of health for young people, and the full development of people's capabilities across the social gradient.

- Inequalities in educational outcomes affect physical and mental health, as well as income, employment and quality of life.

- Reducing inequalities across the social class gradient requires a sustained commitment to children and young people through the years of education.

- Inequalities in educational outcomes are as persistent as those for health and are subject to a similar social gradient.

- Once at school, it is important that children and young people are able to develop skills for life and for work.

3.1 EDUCATION

There is little evidence of a sustained effort towards ensuring school age children with learning disabilities participate in mainstream education. In fact, recent figures show a declining number of children with learning disabilities attending mainstream schools, currently amounting to approximately only 10%. (190)

There are large regional variations and more participation in mainstream education where the local authority runs more schools.

Available data on educational outcomes for people with learning disabilities show that children with a special educational need associated with a learning disability have much lower educational achievement than their peers. (23) However, more positively, from 2007 to 2011 the percentage of children with mild learning disabilities who were assessed as achieving the expected level of attainment in both English and Maths rose from 9% to 15%. (23) These improvements should be maintained. However, the scope of this review did not make it clear how this improvement had been achieved.

It is, of course, unsurprising that academic outcomes for those with learning disabilities are behind the average for the population. A more meaningful set of goals has been implemented for children with learning disabilities, focused on 'Preparing for Adulthood' outcomes – a job, good health, community participation, friends, independent living and supported employment. (197) However, any improvement in these outcomes was not yet evident at the time we conducted this research. (191)

Entry level and Level 1 courses (previously termed Foundation level) appear to have positive impacts on those with learning disabilities. Ofsted concluded these courses may improve experiences for children and young people with learning disabilities, and that course completion and accreditation levels were good. (105) However, Ofsted also noted that additional value lies in the social and emotional learning gained, which is not commonly recorded. Parents interviewed identified social gain outcomes, such as the improved ability of their children to communicate effectively, engage in lessons and speak to unfamiliar adults. Students spoke of valued outcomes such as using the canteen independently and attending school regularly. (105)

3.2 POVERTY AND DISCRIMINATION

Boys with mild to moderate learning disabilities are more likely to live in a poorer household and report significantly worse self-rated health and mental health than their male peers without learning disabilities. (26) For girls, those with learning disabilities are more likely to be exposed to poverty and bullying, but do not have significantly worse mental health compared with their female peers without learning disabilities. (26)

3.3 HEALTH

Public Health England has shown that children and young people with learning disabilities are more likely than those without to live in poverty, have worse mental health and display more risky health behaviours, such as a sedentary lifestyle, poorer diet and substance misuse. (26, 34) We know that educational level is closely linked to health behaviours and therefore adopting healthy habits might be more challenging for this population. (351)

Prevalence of depression was noted to be higher in adolescents with learning disability than in typically developing adolescents. For specific groups, such as those with Down's syndrome, a biologically elevated risk of depression was found, while for other groups with learning disabilities, modelling suggested 'the risks were more often environmentally determined' (26, p10) than directly associated with the learning disability.

In a longitudinal study of children who were born preterm (before 37 weeks), the number of children, many with learning disabilities, who needed glasses or who had one eye that squinted increased with age (from 6–11 years). (193) Further, it is estimated that one in 10 people in

England with a learning disability will be blind or partially sighted, with adults with a learning disability 10 times more likely to have a serious sight problem than the general population, and children with a learning disability 28 times more likely to have a serious sight problem than the general population, and these present at a much younger age than for the general population. (354) In addition, a fifth have a hearing problem. (355) Research indicates that many children entering school have not had a sight or hearing test, and that four in 10 children in special schools have never had a sight test. (354)

Data for 2014/15 from Special Olympics International showed that children age 8–19 years classified with intellectual disabilities were more prone to certain health-affecting conditions than adults with intellectual disabilities. (116) For example, compared across age group categories, children with intellectual disabilities had the second highest rate of untreated tooth decay and the highest rate of never having had an eye exam. (116)

There is regional variation in the provision of annual health checks. In England some regions provide these checks to around 60% of people (aged 14 years and over) with a learning disability known to GPs, while other areas provide health checks to just 30% of this group. (5)

3.4 LIVING IN CARE AND SECURE SETTINGS

In 2013, 35% of children with learning disabilities residing in residential homes were not living in the same area as their families. (59) Good social support networks are important for wellbeing and to mitigate against adversity, and living at a distance from one's family reduces a young person's social support.

If not addressed effectively in the early years, challenging behaviours can escalate. Despite just

2.9% of the whole UK population estimated as having learning disabilities, a quarter of young people in custody have learning disabilities. (61)

The experiences of individuals with learning disabilities residing in secure settings can be extremely distressing. The Children's Commissioner (2017) noted that in secure settings, 'particularly high use of restraint and seclusion was noted in units with a learning disability specialism'. (24) The same report cited evidence that prone restraint can be a 'hugely traumatic and damaging experience' and that there is little evidence to suggest that it is effective in reducing the occurrence of behaviours that challenge. Policy guidance on 'positive and proactive care', issued by the Department of Health and Social Care, (199) recommended that prone restraint never be used. This guidance is not statutory, but its implementation is being monitored by the Care Quality Commission. This is a positive step because any service deemed to be non-compliant will attract criticism and sanctions. (199)

A third of children in young offender institutions, secure training centres and secure children's homes experience isolation and segregation, with some young people spending 22 hours a day isolated from their peers. (24) Isolation is likely to exacerbate feelings of stress, anxiety, anger, depression and hopelessness. Staff in the secure estate report that even short periods of isolation can trigger self-harm, exacerbate the impact of trauma experienced in the past and cause psychotic episodes. (24) The research found that children with a recorded disability were two to three times more likely to have experienced isolation than non-disabled children. (24)

The UK government has accepted a clear mandate to improve practices and increase pressure to move children and young people with more severe mental health problems or with challenging behaviours into

community-based settings and out of residential provision unless all other options have been exhausted, and then only for the shortest period of time possible.

Improved outcomes are only just starting to trickle through. For example, as of April 2018, one of the 'fast track' partnership in Greater Manchester, providing integrated services and support to improve outcomes for children with learning disabilities reported a 30% reduction in the number of in-patients, outperforming the national average of an 18% reduction; the NHSE's target by March 2019 is 35–50% reduction nationally. (188)

Estimates of the annual costs of a residential placement for a person with severe learning disabilities were £178,000 for children (87) and £185,000 for adults (at 2012/3 prices). (88) Meanwhile, Lemmi and colleagues (89) estimated the cost of community care ranging between £39,612 and £74,876 for children, between £35,235 and £52,832 for young people and between £81,478 and £94,799 for adults. These figures suggest that community care is considerably more cost-effective.

3.5 TRANSITION FROM CHILDHOOD TO ADULTHOOD

In 2015, the National Institute for Health and Care Excellence (NICE) undertook a review of the transition from childhood to adulthood. It reported there were many transition policies in existence and well-established local models for supporting and improving transition. However, few had been tested for their clinical or cost effectiveness. NICE reported 'much evidence about the nature and magnitude of the problems of transition from children's to adults' services but very little on what works', (93 p. 25) and very little on GPs' role in the process. It noted that studies used many different outcomes, 'including clinic attendance, biomedical markers, transition readiness, communication levels with service providers, service satisfaction and measures on disability scales' and it was 'not clear which of these was most important when measuring transition success'. (93 p28) This review has made similar findings.

3.6 CHILDREN AND YOUNG PEOPLE: MOVING FORWARD

The Marmot Review's recommendations for children and young people are also valid for people with learning disabilities but more needs to be done. Efforts to maintain improvements in outcomes for children with mild learning disabilities should not be lost and work to build on the style of teaching used for the old Foundation stage courses, which improves social, emotional and communication skills, appears warranted. In addition, preparing children and young people for adulthood, and raising their aspirations regarding work, should enable them to make the most of the Department for Work and Pensions' initiative to ensure that all those on education, health and care plans have a work placement.

The Marmot Review's recommendations to improve the social determinants for households generally will also support this age group. In addition, efforts to improve early years experiences with targeted support as part of an integrated strategy should result in a reduction in both the development of behaviours that challenge and institutionalisation after the early years.

We support the current mandate, set out in NHS England's Building the Right Support, (83) a national plan to improve practices and increase pressure to move children, young people and adults out of inappropriate institutional settings.

The following recommendations are aimed at addressing health issues arising in children and young people with learning disabilities.

Recommendation 4

Change the 'choice architecture' to encourage healthier behaviours. 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.

The majority of people with learning disabilities are keen to work but for those known to local authorities the employment rate is just 5.8%. (200)

Recommendation 5

Eyesight and hearing tests for all. DfE and NHSE should adopt the 'equal right to sight' approach and work together with charities to appropriately design eyesight and hearing tests, administered to all children in special and mainstream schools within their first year of joining.

Recommendation 6

The Department for Education and NHSE should formally require that specific actions are included in the EHCP plan process from the beginning, to ensure take-up of hearing and sight screening tests, improvements in health behaviours and improved action on the social determinants of health

4. WORK AND INCOME

The Marmot Review showed for all adults:

- Good quality work is of central importance to health and a range of other desirable outcomes, providing skills, income, recognition and social status.

- Active labour market policies aimed at supporting people to enter work with interventions such as job search assistance and training programmes, wage subsidies and job creation, have helped to reduce overall unemployment in the general population. However, all countries that have tried to introduce active labour market policies for disabled people have had poor success rates.

- Providing people with good quality work at a fair wage under good working conditions is a matter of social justice, and important for health outcomes.

- Investment in good work results in important returns to the national economy, rather than burdens on public spending.

- A minimum income for healthy living is important to ensure that people have the resources needed to maintain good health. For example, sufficient income is needed to live in accommodation that is free from damp, to have a healthy diet, and to socialise.

4.1. EMPLOYMENT RATES AND BARRIERS TO EMPLOYMENT

Work is important for a number of reasons, but at a fundamental level it provides purpose to life and an income for living. It should therefore not be surprising that evidence has shown that most people with learning disabilities want to work, and they want to work in the same types of jobs as the rest of society. In addition, evidence clearly shows that it is possible to provide supported employment for people with learning disabilities and that doing so can reduce health inequalities. (137)

However, with an employment rate of just 5.8% among those adults with a learning disability who are known to local authorities, (200) and other studies suggesting that about 17% of all working age people with a learning disability have a paid job, (364) society is clearly failing to include those with learning disabilities.

While people in this group do want to work, a lack of available appropriate employment, coupled with reductions in the financial support available for people who need support but declare they are fit for 'work-related activity', could contribute to a low level of ambition among those with learning disabilities and their carers. (147)

> *In 2015, 48 per cent of people with learning disabilities in Vermont were employed in the regular workforce (US average is 19%), all paid at minimum wage or higher by utilising supported employment schemes (152).*

Approximately one-third of family carers of adults with learning disabilities are not in paid employment because of their caring responsibilities. (139) This is likely to result in poorer health outcomes for the carers. For the carer members of our advisory group workshop (on tackling inequalities in health and wellbeing for people with learning disabilities, held in July 2017), it was clear that finding appropriate childcare was extremely difficult, and family members did not trust the quality or level of compassion of the help that was available.

There is strong evidence to suggest that supported employment works for all people with learning disabilities, including those with more severe conditions, although more employment possibilities are available for people with mild conditions than for severe. (113)

Crucial here is an understanding of social welfare policy and the role that the DWP plays in implementing policy, making work possible for people with learning disabilities, and tackling the causes of inequalities. The introduction of Universal Credit (UC) is, for instance, meant to reduce disincentives to work and progress within work. However, research by the Joseph Rowntree Foundation has shown that for many households the introduction of UC will have a negative impact on their incomes after deductions from loss of benefits and taxes are considered. (234)

Long waiting periods that individuals are experiencing for receiving UC are being addressed by the DWP, but the Department needs to work further to understand the impacts of UC and the tax and benefit implications associated with it on the employment rate and incomes of those with learning disabilities.

More positively, the UK government repositioned people with learning disabilities as potential workers rather than recipients of welfare in 2005. The cross-department report Improving the life chances of disabled people set a goal that 'any disabled person who wants a job and needs support to get a job should be able to do so' by 2025. (356) A specific UK target to achieve increased employment rates for people with learning disabilities still needs to be set. Nevertheless, it is encouraging that the current government has set out an ambition to reduce the gap between the employment rate of the overall population and the disabled population, with a goal of getting one million more disabled people into work by 2027, and it has committed to the priority of making a 'step change' in the life chances of people with learning disabilities. (357)

The Joint Health and Work Unit has specifically stated that it wants to ensure that all individuals with education, health and care plans have the opportunity to take up a supported internship where appropriate. (357) This commitment should result in an increase in the numbers of people with learning disabilities in employment, if implemented well. Any such policy should be evaluated.

4.2. OUTCOMES CAN BE BETTER: GOOD PRACTICE EXAMPLES

Statistics on the employment rates of people with learning disabilities shows clear regional variation, of which only a small proportion is explained by variation in national employment rates in 2015/16. The percentage in paid employment varies from 0.3% to 22.1%. These figures clearly illustrate that there is more to be learned from those regions that are doing better. (200)

The 'Place, train and maintain' model is acknowledged to be the most successful employment support models for people with learning disabilities. The supported employee

> *Pharmacist chain Walgreens employs people with cognitive disabilities in its US distribution centres. In 2014, 35% of staff in its distribution centres were disabled.*
>
> *The company has found that people with cognitive impairments are equally productive as, and have less accidents than, people without such a disability. Depending on the site, using this employment strategy reduced staff turnover by between 20 and 50%. (352)*

is taught a specific job, in a specific work place, usually by a skilled job trainer or job coach who provides on-the-job training. Key elements are vocational profiling, job finding, job analysis (breaking down what the job involves) and placement. Job training and follow-along services to monitor and support the person in their new role are the main approaches then used. (149)

The most promising examples of supported work programmes are found in the USA, as demonstrated by the example of Vermont . (152) Walgreens chain employs people with cognitive disabilities in its US distribution centres. In 2014, 35% of the staff in their distribution centres were disabled. The company has found that people with cognitive impairments are equally productive as, and have less accidents than, staff without such a disability. Further, depending on the site, using this employment strategy reduced staff turnover by between 20 and 50%. (352)

Internship models, such as Project Search, have also been shown to successfully support the transition from education to work for people with a learning disability. Project Search originated at the Cincinnati Children's Hospital Medical Center, Ohio, USA in 1996, developing work placements in the hospital for people with intellectual disabilities. It was replicated in the UK during 2010/11 at a variety of sites. By 2014, there were 17 active sites in the UK, with between 5 and 53 students at each site. Seventy-five per cent of these were people with a learning disability and around 10% of people were defined as having a severe or profound learning disability. When 14 Project Search sites were evaluated in the UK in 2013, just under half the sample of participants were in employment, with 36% of those in a full-time job (more than 16 hours per week) and 11% working part-time. (153, 154, 155)

A cost–benefit analysis of 101 Supported Employment Agencies in the UK, (157) where nearly half were supporting 2,446 people with disabilities in jobs (90.3% of whom had a learning disability), showed positive economic gains from providing supported employment to people with learning disabilities. Workers gained £2.47 for every £1 they lost in benefits by taking up employment, and taxpayers received 43p back in savings for each £1 invested. Taxpayer cost–benefit improved over time, recouping 54p for every £1 invested after six years.

Clean Sweep, linked to the Mencap charity, is the oldest example our research found of a business run by people with learning disabilities. It adopted a cooperative model within a company limited by guarantee. Starting out as a cleaning company it now provides part-time work for the 17 worker members who own and run it. In 2011, in its 16th year of trading, turnover was about £30,000 and there were 14 people working from four to 16 hours a week (all with some ongoing reliance on benefits too). (211)

Hartlepool Borough Council attributes a simple overt policy change to its achievement of 15.2% of people with a disability being in paid employment (in 2016–17). This compares with the national average for England of just 5.7%. The change involved moving its adult social care employment link team into the regeneration and neighbourhood services division. This has meant that every employment incentive introduced is also offered to clients who are eligible for social care eligible, including volunteering, education and work placements, increasing opportunities for paid employment for people with a learning disability. (363)

The DWP's Access to Work scheme aims to help people who have a disability or a long-term health condition to start or stay in work. There are two

main types of Access to Work provision: 'Assessments' and 'Elements'. Assessments involve exploring workplace-related barriers to employment and making recommendations on how these can be overcome. Elements are intended to supplement the reasonable adjustments that employers are required to make under the Equality Act 2010. Following a recent promotion of the scheme there has been a 25% increase in the number of people with a learning disability being provided with Access to Work (Elements) provision approved, from 1,210 in 2015/16 to 1,510 in 2016/17. (353)

In 2014/15 NHS England's Equality and Diversity Council made a specific commitment to improving employment opportunities in the NHS for people with a learning disability and 113 organisations pledged to employ people with learning disabilities. At least 58 jobs were reported to have been created, above the internal target of 50 jobs. (358)

4.3 MAINTAINING INCOMES

In cases where people with learning disabilities are unable to find meaningful work, or are unable to enough work to maintain a decent standard of living, there is a need to ensure that they have a sufficient income to live a healthy life, choose healthy options and participate in social events.

To mitigate the physical and mental health impacts of being on a low income, more generous social protection policies would reduce the impacts on diet and housing quality, and on associated stress, and would be beneficial for health.

Not having sufficient income to support good health can lead to higher health costs later in life. Lifetime accounting of the benefit of higher incomes might be beneficial to support informed policy making.

4.4 WORK AND INCOME: MOVING FORWARD

People with learning disabilities want to make an active contribution to society; they want to work, they want value and purpose; yet employment rates for this group are extremely low. (200) Clearly this situation can be improved, as the statistics on supported employment programmes in the UK and the US have demonstrated. The best-performing local areas in England are currently achieving a 22% employment rate for people with learning disabilities (359) – more now needs to be done to spread best practice more widely.

To coincide with the new policy paper on disability and employment published by the Joint Health and Work Unit in November 2017, (357) the Department for Education announced £9.7m of additional funding for local authorities to set up local supported internship forums and provide job coach training, which will benefit young people with a learning disability. (125) Local areas should be encouraged to make use of this substantial pot of funding to raise employment levels. In addition, the DWP is developing the Access to Work scheme and new support for learning-disabled users of social service, to help more severely disabled people have opportunities to work. (357)

Recommendation 7

DWP and DHSC, with the Joint Health and Work Unit (JHWU), should learn from trials and existing programmes, and work with local authorities and employers to ensure that employment offers for people with learning disabilities are available nationally, and provide stakeholders with a timetable that delivers this as rapidly as possible.

Recommendation 8

The Government, specifically DWP and DHSC, should undertake a systematic review of how it supports people with learning disabilities, ensuring that access to work, homes, benefits, health and care services and education are adequate. A review of the sufficiency of the personal budget for EHC plans is advised, to identify whether or not this is being adequately rolled out to those in most need.

5. DISCRIMINATION

The Marmot Review showed for all people:

- Discrimination interacts in complex ways with socioeconomic position in shaping people's health status.

- Discriminatory practices compound existing socioeconomic disadvantage.

- Age, gender and ethnic differences in health outcomes heighten such discriminatory practices.

- Discriminatory practices may be covert or overt, but either way cause psychosocial stress and toxic effects.

- An awareness of the attitudinal changes needed to ensure people are treated on an equal, non-discriminatory basis is vital.

5.1. THE NATURE OF DISCRIMINATION

People with learning disabilities are more likely than the general population to suffer from discrimination, poor access to some health services and worse employment prospects as a result of their disabilities, all of which can impact negatively on their health. Discriminatory public attitudes towards people with learning disabilities can restrict where they go, how safe they feel, how they travel and who they speak to, and result in feelings of low self-esteem, worry, anxiety, stress and other mental health issues. (103) Discriminatory attitudes have direct and profound social and psychosocial impacts that limit community connectedness, health and wellbeing.

In a survey of the general population, three-quarters of people were not able to give an accurate example of a 'learning disability'. The capabilities of people with learning disabilities are commonly misconceived and often underestimated. However, in reality 80% of people who meet the criteria for having a 'learning disability' have a mild or moderate disability and are able to act largely independently in their everyday lives. (103)

Discrimination can be covert and is sometimes unintended, based on misconceptions regarding capacities and abilities, for example. However, overt discrimination is also widely experienced by people with learning disabilities. This manifests in exclusion from activities and opportunities, name-calling, bullying, being stared at, and being targeted by hostility. (104)

36% of people with learning disabilities in the UK said that over the past year they had experienced hostility, aggression or violence from a stranger because of their learning disability. (220)

Police data shows an increase in disability hate crime between 2011 and 2016. Of the 43,748 hate crimes recorded in England and Wales in 2011/2012, 1,744 (4%) were disability-related hate; this figure increased by 107% to 3,629 recorded cases in 2015/16. (237)

However, disability-related bullying and hate crime have not been picked up, accurately recorded or taken seriously by police in the UK, according to the Children's Commissioner. (238, 239, 240) In 2011, fewer than 2,000 such crimes were reported to police forces in England and Wales and of those, only 523 resulted in a conviction. (241)

Hate crime against people with learning disabilities is most likely to involve a single perpetrator (59% of reported cases). (242) In one study, most victims with a learning disability know the perpetrator, (242) and other research shows that perpetrators are likely to have access to the victim's finances and their home. (243) The most commonly alleged perpetrators are social care staff (28%), another vulnerable adult (21%), another family member (excluding partners), 14% or an unknown perpetrator (12%). (43)

The most common types of alleged abuse concerning adults with learning disabilities are physical abuse (38%), followed by emotional/psychological abuse (18%), neglect (18%), financial abuse (13%) and sexual abuse (9%). (43) Allegations of abuse concerning adults with learning disabilities in 2011/12 were substantiated in a third of cases. (43)

People with learning disabilities may be more likely to have limited rehousing options and/or access to alternative carers, making it more difficult for them to report or escape their experiences of abuse. Perpetrators of some types of abuse can act as 'pretend' friends (this is sometimes referred to as 'mate crime'), who use their perceived friendship to take advantage of the victim, their money or other resources, or to develop a long-term abusive relationship. (43)

5.2. OUTCOMES CAN BE BETTER: GOOD PRACTICE EXAMPLES

The current evidence base offers few conclusions to provide guidance to policy-makers or programme commissioners. However, actions can be taken to prevent the everyday latent discrimination that emanates from a lack of understanding of people with learning disabilities. In particular, greater integration of children with learning disabilities into mainstream schools, such as in Tanzania, and of adults into workplaces, can help reduce misconceptions. (103)

One of the clear messages from the research is that in the majority of severe cases of abuse, neglect and violence, the person with the learning disability knows the perpetrator. Given the importance of the few relationships that people with learning disabilities may have, it is important that carers and family are supported in their role as care providers for people with learning disabilities. Poor social determinants of health will exacerbate stress, and so efforts to tackle unemployment, low income and poor housing and to support carers, with measures to reduce reliance on one person, should be considered, alongside respite care.

In Tanzania the government has allowed people with learning disabilities to go to mainstream schools by establishing classes within those schools at primary level and total inclusion at secondary level.

After primary school, those who exhibit some improvement are enrolled in centres where skills development and practical lessons are taught. Such centres are funded by the Government. (81)

Recommendation 9

PHE, local authorities and NHSE should support coordinated campaigns for greater integration of people with learning disabilities into mainstream society, to reduce discrimination and stigma and support representation. This should include a push towards more inclusion of children with learning disabilities within 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 learning disabilities.

Recommendation 10

A hearts and minds campaign is recommended, led by a collaboration 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.

6. SOCIAL PARTICIPATION

The Marmot Review showed for all adults:

- Social capital – the links between individuals that bind and connect people within and between communities – provides a source of resilience and a buffer against risks of poor health.

- Social capital works by providing social support, which is critical to physical and mental wellbeing, and the networks that help people find work, or get through economic and other material difficulties.

- Individual empowerment requires social action.

- Building healthier and more sustainable communities involves choosing to invest differently.

- Feelings of low status and of lacking social networks are significant sources of stress throughout the population.

6.1 SOCIAL CONNECTIONS

Half of all people with a learning disability experience chronic loneliness, compared with around 15 to 30% of people in the general population. (307)

The figures are stark. One study found that one in three people with learning disabilities find themselves stuck indoors on a Saturday, unable to take part in leisure activities. Nearly half (49.3%) would like to spend more time outside their house. (314) Another survey showed that people with learning disabilities spend 75% of their time with no contact from staff or anyone else and received support for only about five minutes per hour. (316)

As in the general population, among people with a learning disability loneliness has been associated with health risks such as depression and stress. (308, 309) Loneliness is directly linked to health risks, such as high blood pressure and higher mortality risk. (307, 310) Holt-Lunstad et al. (311) found that across 148 studies (involving a total of over 300,000 people) the participants with stronger social relationships had a 50% less risk of mortality than people with less developed social relationships. The magnitude of this effect is greater than that of many well-known mortality risk factors, such as obesity and physical inactivity. (311)

More key evidence on social networks and friendships

1. Children and adults with a learning disability usually have smaller social networks, and weaker and more distant social relationships, than those without a learning disability. (300, 301, 303)

2. One-third of children with a learning disability say they find it hard to make friends, in comparison with 9% of children without a learning disability. (302)

3. For adults with a learning disability, it is common to have relationships only with the people they live with and with support staff. (298, 303)

4. 41% of adults with a learning disability do not have more than yearly contact with family members they do not live with. (304)

5. People with profound and multiple learning disabilities are less likely to participate in social and leisure activities than those with a mild, moderate or severe learning disability. (304)

6. Friendship needs of people with profound and multiple learning disabilities are often ignored, yet people with these conditions are capable of forming relationships, making choices and communicating with others through vocalisation or touch. (305)

In a study of 37 adolescents with learning disabilities, the participants reported that what constitutes good wellbeing for disabled young people differs little from that of their non-disabled peers – positive family relationships, good friendships, social interaction and participation. (284) What varied for them was the high reliance on family/carers in facilitating opportunities to take part in activities and engage socially with their peers, for example through the provision of transport. Activities they valued included attending formal clubs and societies and respite services. They needed activities to go to, like most teenagers. They recognised that good psychological wellbeing was characterised by having aspirations, choice, autonomy, self-determination and a sense of reaching their potential. Negative experiences included bullying, disrespect, dependence, lack of choice and over-protectiveness from parents. (284)

The charity Mencap has drawn up a list of barriers to gaining a social life and friendship for people with learning disabilities. (299) We took these barriers and came up with positive elements that would potentially enable people with learning disabilities

Elements to improve social life – from Mencap evidence
Good communication to find out what people like to do
Accessible activities and events
Support and contact, particularly in the evenings and at weekends
Avoiding the need for people with a learning disability to leave events early – e.g. by not having support workers on shift changes
Easy-to-read information about events, including information about accessibility of facilities
Self-confidence and social skills
Money to pay for entrance fees, transport, and accompanying support workers (plus their entrance fee)

6.2. OUTCOMES CAN BE BETTER: GOOD PRACTICE EXAMPLES

There are initiatives that have been shown to be effective in improving social connections. For example, after participating with a Best Buddies scheme, which initiates and supports friendships between disabled and non-disabled people, three-quarters of people with learning disabilities reported in a 2014 survey feeling more accepted by their friends and in their communities, and 55% reported feeling more confident in engaging with other online social networks. (327)

Interventions to increase the possibility of making friendships for people with learning disabilities, often within the structural restrictions of caring, are starting to emerge, though they are small in terms of their impact at present. The Stay Up Late Campaign is a charity promoting active social lives for people with learning disabilities. (306) It runs an active Twitter campaign, with 16,600 followers, potentially providing a good example of the harnessing of modern social media for people with learning disabilities to connect and organise their own campaigns. Based on workshops about the freedoms that people with learning disabilities want, conducted over a three-year period, Stay Up Late has drawn up a 'Magna Carta' that sets out a range of freedoms – to choose support staff, to have happy support staff, to choose friends and have a social life, to choose where to live and to have the right to have a relationship and a sex life.

Stay Up Late has helped set up a number of 'Gig Buddies' projects in the UK. Set up by the Sussex branch in 2012, Gig Buddies is a volunteer befriending initiative for adults with mild to moderate learning disabilities. The scheme aims to match people with learning disabilities who like going out to gigs and events with volunteers who like the same types of music. (306) Volunteers are matched with clients and Gig Buddies are then encouraged to go out to a gig at least once a month at a mainstream venue. Gig Buddies also organise their own social events. No figures are available for the numbers of people involved as yet, but the model is becoming popular internationally. Brighton Stay Up Late is now a social franchise. Gig Buddies Scotland was launched in 2015 and Gig Buddies Sydney is now well established.

6.3 SOCIAL PARTICIPATION: MOVING FORWARD

We would expect that some of the recommendations intended to reduce discrimination outlined in the previous chapter would have a positive impact on social isolation. For example, the hearts and minds campaign might include more positive imagery and representation regarding people with learning disabilities from publicly funded bodies such as the BBC, which may help to break down some barriers between the general population and the population of people with learning disabilities.

However, this alone may be insufficient and clearly more needs to be done to reduce loneliness and social isolation for this group.

Recommendation 11

Friendship support groups should be made available to all people with learning disabilities. As part of education, health and care 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, and professionals should be required to link people with appropriate friendship support groups.

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