

PE1545/W

Scottish Learning Disabilities Observatory submission of 17 April 2018

Thank you for your correspondence dated 20.3.18 which asked the Scottish Learning Disabilities Observatory:

1. To provide more information about its work programme aimed at addressing the diverse needs of people with learning disabilities in Scotland, and
2. To provide the views of the Observatory in relation to the specific action being called for in petition PE145.

In response, I attach an outline of the Observatory work programme. This was established in 2015 with funding from the Scottish Government to “..understand more about the health inequalities faced by people with learning disabilities and to make those needs more overtly visible..”. This programme was agreed with the funder, and is shaped by the Scottish Learning Disabilities Observatory Steering Committee (membership shown below). Its ongoing development will be aligned to future implementation priorities in *The Keys to Life* strategy.

In relation to the second point I request that the Committee refers to my [previous correspondence](#) on this, dated 31.7.15.

Scottish Learning Disabilities Observatory Steering Committee membership

Associate Professor Linda Allan, Strategic Clinical Lead/Professional Advisor-Learning Disabilities Policy, Health and Social Care Integration Directorate, Scottish Government

Professor Sir Kenneth Calman, The Chancellor, University of Glasgow (Chair of the Steering Committee)

Mr Chris Creegan, Chief Executive, Scottish Commission for Learning Disability

Dr Colin Fischbacher, Clinical Director for Information Services, Information Services Division, NHS National Services Scotland

Dr Andrew Fraser, Director of Public Health Science, NHS Health Scotland

Ms Rona Laskowski, Strategic Programme Manager-Learning Disabilities, NHS Lothian

Dr Phil Mackie, Lead Consultant in Public Health, Scottish Public Health Network

Dr Gerry McCartney, Scottish Public Health Observatory, NHS Health Scotland

Mr Duncan McIntyre, Chair of Learning Disabilities Practice Network, Social Work Scotland

Mr Neil Mellon, Primary Care Division, NHS Ayrshire and Arran

Professor Craig Melville, Professor of Intellectual Disabilities Psychiatry, University of Glasgow

Ms Jenny Miller, Chief Executive Officer, Profound and Multiple Impairments Service (for people with profound learning disabilities)

Professor Chris Philo, Professor of Geography, University of Glasgow

Ms Pandora Summerfield, Chief Executive Officer, Down's Syndrome Scotland

Professor Carol Tannahill, Chief Social Policy Advisor, Scottish Government

Ms Fiona Wallace, Member, People First Scotland

Professor Nicholas Watson, Professor of Disability Studies, University of Glasgow

Work Programme

	PROJECT & FURTHER INFORMATION	METHOD	RELEVANCE TO POLICY & PRACTICE
1	<p>Management of long-term conditions in primary health care for adults with learning disabilities</p> <p>https://www.sldo.ac.uk/projects/primary-health-care/long-term-health-conditions-management-and-learning-disabilities/</p>	<p>Cohort study from 2007-2014. Completion on health care indicators compared with the general population in NHS Greater Glasgow and Clyde</p>	<p>Good health care and health promotion is a pathway to health improvement. We found people with learning disabilities receive poorer primary health care than the general population, but crucially, following health checks and learning disabilities-primary care liaison within NHS Greater Glasgow and Clyde, we have demonstrated a narrowing of the health care inequality gap over time. This is good practice to share across Scotland, and suggests the need for policy consideration regarding national provision of health checks for adults with learning disabilities.</p>
2	<p>Prevalence and general health status of children, young people and adults with learning disabilities</p> <p>https://www.sldo.ac.uk/projects/health/census-2011-people-with-learning-disabilities</p>	<p>Analysis of general health data from people with learning disabilities compared with the general population using Scotland's Census, 2011</p>	<p>We found substantially lower general health ratings and a greater limiting effect on daily activities. This was across the lifespan for people with learning disabilities, including in early childhood. Specialist learning disabilities services have traditionally had a focus on skill development, mental health, challenging behaviours and epilepsy. This study demonstrates the need to raise professional awareness to pay greater consideration and time on general health needs of people with learning disabilities.</p>
3	<p>Prevalence of mental health conditions and relationship with general health in children, young people and adults with learning disabilities</p> <p>https://www.sldo.ac.uk/projects/health/census-2011-people-with-learning-disabilities/</p>	<p>Analysis of mental health data from people with learning disabilities compared with the general population using Scotland's Census, 2011</p>	<p>Mental health conditions were more prevalent across the lifespan for people with learning disabilities, and were associated with poorer general health. A combination of poor mental and general health is associated with negative health outcomes, such as premature death. This study demonstrates a need to improve understanding of the relationship with mental and general health in the population with learning disabilities to help influence the development of appropriate interventions, and health and social care policy.</p>

4	<p>Health conditions in people with autism</p> <p>https://www.sldo.ac.uk/projects/autism/autism-and-health/</p>	<p>Systematic review of systematic reviews and meta-analyses</p>	<p>There is emerging evidence that people with autism have a different pattern of health conditions compared with the general population, and may be at higher risk of suicide. This review identified what we know on this topic and where knowledge gaps remain. Professionals need this information to develop guidelines and training for improved detection and interventions aimed at improving quality of life for people with autism. This is closely aligned to values at the core of the Scottish Strategy for Autism recommendations.</p>
5	<p>Prevalence of long-term health conditions in a whole country population of 25,063 children and young people known to have autism</p> <p>https://www.sldo.ac.uk/projects/health/census-2011-people-with-autism/</p>	<p>Analysis of comorbid conditions data for children and young people aged 0-24 with autism compared with the general population using Scotland's Census 2011</p>	<p>We found that children and young people with autism were 11 times more likely to report poor general health, 50 times more likely to report intellectual disabilities and 16 times more likely to report mental health conditions. Females with autism had more of each comorbid condition than males, including intellectual disabilities, suggesting they may have more severe autism than the males. It is important to raise clinicians' awareness of this extent of comorbidity, and to have accurate prevalence data to plan appropriate prevention and intervention measures, and to follow health inequality trends.</p>
6	<p>Prevalence of long-term health conditions in a whole country population of adults known to have autism</p> <p>https://www.sldo.ac.uk/projects/health/census-2011-people-with-autism/</p>	<p>Analysis of comorbid conditions data for adults aged 25+ with autism compared with the general population using Scotland's Census 2011</p>	<p>The likelihood of having sensory impairments, intellectual disabilities, mental health conditions, physical disabilities, and other conditions was between 3 and 95 times higher in the population with autism than the general population. Within the population with autism, females were more likely than males to have intellectual and physical disabilities and other conditions, more so than in the whole population.</p> <p>Clinicians need heightened awareness of comorbidities in autism to provide suitable care and support, especially given the added complexity of assessment in this population and the hearing and visual impairments, which may impact on reciprocal communication and exacerbate underlying difficulties in autism.</p>

7	<p>Prevalence, age at identification, and general health status of children and young people known to have autism - a whole country population cross-sectional study</p> <p>https://www.sldo.ac.uk/projects/health/census-2011-people-with-autism/</p>	<p>Analysis of general health of children aged 0-24 with autism compared with the general population using Scotland's Census 2011</p>	<p>Children and young people known to have autism (n=25,063) comprised 1.6% of the total population of 0-24-year olds in Scotland (n=1,548,819). There were 19,880 (79.3%) males and 5,183 (20.7%) females with autism. 21.9% of children and young people with autism, and 1.9% without autism reported poor health. Children and young people with autism were 11 times more likely to report poor general health, especially females. Their poorer general health is prevalent at all ages, meriting attention across the full lifecourse, from the point of autism diagnosis.</p>
8	<p>Prevalence, age at identification, and general health status of adults known to have autism - a whole country population cross-sectional study</p> <p>https://www.sldo.ac.uk/projects/health/census-2011-people-with-autism/</p>	<p>Analysis of general health status data for adults aged 25+ with autism compared with the general population using Scotland's Census 2011</p>	<p>Adults known to have autism (n=6,649) comprised 0.2% of the total population of people aged 25+ in Scotland (n=3,746,584). There were 4,610 (69.3%) males and 2,039 (30.7%) females known to have autism. 46.8% of adults with autism, and 23.7% without autism reported poor health. Adults with autism were 5 times more likely to report poor general health, especially females and older people aged 65+. Existing evidence is limited, yet very much needed to accurately plan for appropriate prevention and intervention measures and service provision.</p>
9	<p>Mental ill-health and its determinants in mothers caring for a son or daughter with learning disabilities across and beyond the caregiving trajectory: secondary data analysis and data linkage of administrative and health records in Scotland</p> <p>https://www.sldo.ac.uk/projects/maternal-mental-health/</p>	<p>Cross-sectional case controlled cohort study of an estimated 9,250 mothers of a son or daughter with learning disabilities</p>	<p>Little is known about the prevalence of mental ill-health of maternal carers of a son/daughter with learning disabilities across the caregiving trajectory, including post caregiving, and the factors that compound or mitigate against it. This study will provide unique insights into the multiple social determinants of health that impact on health outcomes of maternal carers. This research will answer important and overdue questions on mental ill-health which will subsequently identify gaps in current services and provide evidence to inform professional support for mothers at pivotal points in the caregiving trajectory including post caregiving.</p>
10	<p>The prevalence and types of</p>	<p>Cross-sectional study of 1,023</p>	<p>Failure to identify health conditions and diagnostic</p>

	<p>physical ill-health in adults with learning disabilities with and without Down syndrome</p> <p>https://www.sldo.ac.uk/projects/health/physical-health/</p>	adults with learning disabilities	overshadowing are common for people with learning disabilities. Healthcare professionals and carers need information about the presentations and demographics of commonly occurring conditions, so they can identify and report problems in a timely manner and thus prevent unnecessary suffering from potentially serious, painful and/or disabling conditions. We found multi-morbidity in 98% of adults with learning disabilities and at all ages, not just in middle and old age. Policy and practice development on multi-morbidity is relatively recent. It needs to be relevant across the life course for people with learning disabilities, and regardless of the type of neighbourhood they live in.
11	<p>Prevalence, types, and associations of medically unexplained symptoms in adults with learning disabilities</p> <p>https://www.sldo.ac.uk/projects/health/physical-health/</p>	Cross-sectional study of 1,023 adults with learning disabilities	This study found that people with learning disabilities have substantial additional unexplained symptoms and signs, some of which are painful or disabling. These findings can be used to develop the content of health checks, which should not just focus on management of long term conditions and health promotion (which has tended to be the focus in England).
12	<p>Oral health of adults with learning disabilities and its determinants</p> <p>https://www.sldo.ac.uk/projects/health/oral-health/</p>	Longitudinal cohort study of adults with learning disabilities	We found very poor oral health in this population, and high levels of toothlessness. Oral problems are painful, impede eating and nutrition, and impact on quality of life. We are investigating the causes of this, which appear to be more complex than just poor daily care and access to services for check-ups and treatment.
13	<p>Understanding the levels and inter-relationships of dental and medical complexity in adults with learning disabilities</p> <p>https://www.sldo.ac.uk/projects/health/oral-health/</p>	Secondary analysis and record linkage using GP records, Management Information & Dental Accounting system, and Prescribing Information System, in 4,000 adults with learning disabilities	We will study the role of anticholinergic burden and sugared liquid medicines in oral health problems. There is thought to be over-prescribing of drugs with these effects in people with learning disabilities (e.g. antipsychotic drugs), and lack of awareness of dental consequences in prescribers. If relationships are found, this will give further evidence to prescribers to avoid unnecessary repeat prescriptions, and to

			carers for extra vigilance in supporting oral hygiene in this group.
14	<p>A decade of psychotropic prescribing for adults with learning disabilities</p> <p>https://www.sldo.ac.uk/projects/health/psychotropic-prescribing/</p>	Analysis of 10 year trends in psycho-tropic prescribing in a cohort of adults with learning disabilities, with record linkage to Prescribing Information System, and GP clinical data	People with learning disabilities are prescribed antipsychotics at rates higher than reported rates of mental ill-health. These drugs can have significant health side-effects, including sudden death; NICE guidelines recommend regularly review and reduction. We found a slight decline in newly prescribed antipsychotic medications and a marked increase in antidepressant prescribing. Supporting appropriate prescribing is aligned with the strategic direction of <i>The Keys To Life</i> . This study will feedback trends to prescribers, helping them to meet good practice targets.
15	<p>Prescribing trends in children and young people with learning disabilities, and with autism</p> <p>https://www.sldo.ac.uk/projects/health/psychotropic-prescribing/</p>	Record linkage of Scotland's Pupil Census with Prescribing Information System	This study will find out if antipsychotic prescribing is increasing over time for these groups, and the variability of this across Scotland. This will enable good practice recommendations and targeted actions to be made for prescribers.
16	<p>Children and young people with learning disabilities, and with autism in Scottish schools</p> <p>https://www.sldo.ac.uk/projects/children-young-people/pupil-census/</p>	Secondary analysis of Scotland's Pupil Census data	This study provides information about schooling trends for children and young people with learning disabilities and autism in Scotland. This information is important to support Scottish learning disabilities policy, given the drive to supporting learning in mainstream schools for children and young people with additional support needs.
17	<p>Hospital admissions for physical conditions for people with learning disabilities</p> <p>https://www.sldo.ac.uk/projects/secondary-healthcare/hospital-admissions/</p>	Systematic review	We found that people with learning disabilities have more admissions in medical and dental, but not surgical specialities than the general population, but there is a shortage of evidence as to whether this relates to their higher level of morbidity compared with the general population, and whether admissions are higher for ambulatory care-sensitive conditions (conditions that do not lead to admission if managed well in primary care). It highlights where to prioritise training of secondary care staff

			on the needs of people with learning disabilities.
18	<p>Health care quality for children and young people with learning disabilities, and with autism</p> <p>https://www.sldo.ac.uk/projects/secondary-healthcare/hospital-admissions/</p>	Record linkage of Scotland's Pupil Census with Scottish Morbidity Record 01	<p>This study will determine if rates of admissions for ambulatory-care sensitive conditions – specifically diabetes, asthma, and epilepsy – are higher than for children and young people with these conditions who do not have additional support needs. This is a marker of health care quality, so will raise awareness with practitioners and carers of any problems identified, and can be used as an indicator of trends in health care quality over time for policy-makers.</p>
19	<p>Life expectancy and causes of death of people with learning disabilities</p> <p>https://www.sldo.ac.uk/projects/mortality/life-expectancy/</p>	Systematic review	<p>This study found that people with learning disabilities die on average 20-25 years earlier than the general population, and identified the high risk groups. Causes of death differ to the general population and about 40% of deaths are potentially amenable to health care. Standardized mortality rates are higher for women than for men for reasons that we don't yet know (women with learning disabilities have a greater health inequality with the general population). This requires further study, and work to support policy-makers.</p>
20	<p>Causes of death in children and young people with learning disabilities and with autism</p> <p>https://www.sldo.ac.uk/projects/mortality/life-expectancy/</p>	Record linkage of Scotland's Pupil Census with National Records of Scotland death records	<p>It is important to understand causes of death, as a proportion will be preventable and/or amenable to health care. The causes of death in children and young people are likely to differ from those in adults, and from the general population. This study will find out about this, and could therefore identify what further interventions and/or policies are needed to reduce inequalities.</p>
21	<p>Life expectancy and causes of death of people with Down syndrome</p> <p>https://www.sldo.ac.uk/projects/mortality/life-expectancy/</p>	Systematic review	<p>This study will provide information on life expectancy and causes of death of people with Down syndrome compared to the general population, and trends over time. Changes in lifespan are important to quantify. This will help in planning services and resources to support this ageing population.</p>

22	<p>Trends in infant mortality and childhood survival in children with Down syndrome</p>	<p>Regional genetics unit data linked to NRS death records, and Scottish Morbidity Record 01</p>	<p>Historically, deaths of children with Down syndrome are most common in the first year of life, due to congenital heart disease and respiratory problems. We will determine trends in mortality and survival, given access to and advances in surgery. We will also investigate patterns in hospital admissions for children and young people with Down syndrome. Parents need information on outcomes to help with difficult decisions at the time of foetal diagnosis, and to help them plan to support their child. Access to surgery should be equal for all children who need it.</p>
23	<p>The physical and mental health of people with comorbid autism and learning disabilities</p> <p>https://www.sldo.ac.uk/projects/health/census-2011-people-with-learning-disabilities-autism/</p>	<p>Analysis of health data from people with learning disabilities and autism compared with the general population using Scotland's Census, 2011</p>	<p>About 20% of people with learning disabilities have autism, and about 20% of people with autism have learning disabilities. This study examines whether their needs differ from people with just one of these conditions, and the extent of difference from the general population. This may have implications for service planning and for policy, dependent upon the study findings.</p>
24	<p>Prevalence of long-term health conditions in a whole country population of people with comorbid autism and learning disabilities</p> <p>https://www.sldo.ac.uk/projects/health/census-2011-people-with-learning-disabilities-autism/</p>	<p>Analysis of comorbid conditions data for people with comorbid autism and learning disabilities compared with the general population using Scotland's Census 2011</p>	<p>About 20% of people with learning disabilities have autism, and about 20% of people with autism have learning disabilities. This study examines whether the prevalence rates of long-term health conditions differ for this group when compared with the general population. This may have implications for service planning and for policy, dependent upon the study findings.</p>
25	<p>Trends and variation in per capita spending on services for adults with learning disabilities by individual Health Boards and Local Authorities for 2012/13, 2013/14 and 2014/15</p> <p>https://www.sldo.ac.uk/projects/other</p>	<p>Secondary analysis of data from Information Services Division and NHS National Services Scotland</p>	<p>Our study shows that austerity has impacted on Scotland's expenditure on adult intellectual disabilities services, by not keeping abreast of rises in living costs, and with much variation across areas. This suggests that health and social care are not equitable across the country for adults with intellectual disabilities. This information will help guide service planning and design across Scotland. We now have baseline</p>

	r-health-determinants/spending-on-services/		expenditure data for the whole country with which the trends following post health and social care integration can be measured, to support future research on health and social care outcomes.
26	<p>Mental health admissions for adults with learning disabilities in 2014 & 2016</p> <p>https://www.sldo.ac.uk/projects/secondary-healthcare/inpatient-bed-census/</p>	Analysis of Scotland's Mental Health and Learning Disabilities Census 2014 and 2016 (within area and out of area beds)	Patients with learning disabilities are considerably more likely to be admitted under the mental health act, and to experience delayed discharge compared with other people. This suggests they are more severely ill at the point of admission, and there is a need for concerted action and greater flexibility in planning discharge supports and service redesign. The Census analysis allows progress over time to be assessed.
27	<p>What is the effect of transition from school to adulthood on health and wellbeing in young people with learning disabilities?</p> <p>https://www.sldo.ac.uk/projects/children-young-people/transition/</p>	Systematic review	We found issues related to obesity, sexual health and social conflict over transition. However, the evidence base was small and had considerable gaps, despite parental concerns on transition having been expressed for many years. The study findings have identified areas for further work to build upon what is already known, and to address gaps.
28	<p>The impact of transition from school to adulthood on health and wellbeing in young people with learning disabilities</p> <p>https://www.sldo.ac.uk/projects/children-young-people/transition/</p>	Secondary analysis of data from Scotland's Census 2011, and a qualitative study	<p>Both physical and mental health are poorer in young people with learning disabilities aged 16-24 than those without learning disabilities. Among the population with learning disabilities, those aged 19-24 (who have transitioned from school) are more likely to have mental health conditions than those aged 13-18 (who are still in school).</p> <p>Themes identified were emerging mental health problems including anxiety and challenging behaviours, with lack of support during transition and limited appropriate options for post-school activities contributing. Support for families during the transitional period is essential.</p>
29	Impact of hate crimes and targeted	Narrative review and qualitative	Issues with police coding of hate crimes have been identified

	<p>violence on health and wellbeing of people with learning disabilities</p> <p>https://www.sldo.ac.uk/projects/other-health-determinants/hate-crime/</p>	<p>study with people with learning disabilities, their families, carers, representatives from disabled people's organisations, and Police Scotland</p>	<p>and reported. Themes will be identified and drawn together to identify the extent and impact of hate crimes. All data has been transcribed and is now currently being coded and analysed by thematic analysis using NVivo11 qualitative data analysis software. Emergent themes thus far (from participants with LD) are centred around fear, anxiety, depression and wellbeing in relation to violence and hate crime.</p>
30	<p>Reproductive health of women with learning disabilities</p>	<p>Qualitative study (focus groups and interviews with women with learning disabilities) with Engender Scotland, exploring the reproductive health journeys of women with learning disabilities</p>	<p>Commencing 2018, this project is investigating women with learning disabilities' experiences of accessing reproductive health care (sexual health care, pre/anti/post-natal care, menstruation and menopause).</p>
31	<p>The relationship between physical ill-health and mental ill-health in adults with learning disabilities</p>	<p>Cross-sectional study of 1,023 adults with learning disabilities</p>	<p>This project found that the extent of physical multi-morbidity in the population with learning disabilities is overwhelming, such that associations are not found with mental ill-health. Mental health interventions and preventative measures are essential for the entire population with learning disabilities and should not be focussed on subgroups based on overall health burden.</p>
32	<p>Older parent carers health and its reciprocal effect on their ageing offspring with learning disabilities: a record linkage study</p>	<p>Observational study of all older parent carers (n = 3000+) and their offspring with learning disabilities living in Scotland</p>	<p>Parents caring over a prolonged period of time for their offspring with learning disabilities may be at particular risk of poor health, and both mental and physical health may deteriorate the longer the carer has been caring. Little attention has been paid to the health of older parent carers and the health of their ageing offspring with learning disabilities, including how poor health in one affects the other, and the factors that increase or decrease the risk of poor health. We will link health databases to investigate the extent of physical and mental ill-health of ageing parent carers and their ageing offspring, compared with the general population and what determines this ill-health.</p>

33	<p>SPIRE Learning disabilities primary care data project</p> <p>https://www.sldo.ac.uk/projects/primary-health-care/learning-disabilities-spire-data-project/</p>	<p>Development of a bespoke extraction of learning disabilities and autism data from GP systems using the national SPIRE system to understand comorbidity profile and psychotropic drugs prescribed for learning disability population and compare with that of general population.</p>	<p>This project will support the delivery of a central aim of Scottish Government learning disabilities policy which is to increase understanding the health and health needs of this population in order to improve policy and practice. This project will also act as a pathfinder for the development of future bespoke data extractions from GP held data for the purposes of service audit and research.</p>
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