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*Connecting evidence, policy and practice*

**Project summaries**

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| **PROJECT** | **METHOD** | **RELEVANCE TO POLICY & PRACTICE** | **STATUS** |
| Management of long-term conditions in primary health care for adults with learning disabilities compared with the general population: a comparison over time <https://www.sldo.ac.uk/projects/primary-health-care/long-term-health-conditions-management-and-learning-disabilities/> | Cohort study from 2007-2014. Completion on health care indicators compared with the general population in NHS Greater Glasgow and Clyde  | 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. | Dissemin-ating |
| Prevalence and general health status of children, young people and adults with learning disabilities in Scotland<https://www.sldo.ac.uk/projects/health/census-2011-people-with-learning-disabilities/>  | Analysis of health data from people with learning disabilities compared with the general population using Scotland’s Census, 2011  | 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. Further work is required to understand the determines of this substantial health inequality.  | Dissemin-ating |
| Comorbid health conditions in people with autism<https://www.sldo.ac.uk/projects/autism/autism-and-health/> | Systematic review of systematic reviews | 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 will identify 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 and its recommendations. | In progress |
| Health needs of children, young people and adults with autism<https://www.sldo.ac.uk/projects/health/census-2011-people-with-autism/> | Analysis of health data from people with autism compared with the general population using Scotland’s Census 2011 | We found that children, young people and adults have poorer general health than the age, gender matched general population. It is important to know the extent of the inequality gap to plan resources and care in an informed way. The reasons for this inequality are not yet understood, and will be important to identify, as a starting point to prevention and identification of interventions.  | Dissemin-ating |
| The prevalence and types of physical ill-health in adults with learning disabilities with and without Down syndrome<https://www.sldo.ac.uk/projects/health/physical-health/>  | Large cohort study of 1,023 adults with learning disabilities | Failure to identify health conditions and diagnostic 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, whereas it is a problem of middle and old age in the general population. 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.  | In progress |
| Prevalence, types, and associations of medically unexplained symptoms and signs in adults with learning disabilities<https://www.sldo.ac.uk/projects/health/physical-health/>  | Large cohort study of 1,023 adults with learning disabilities | This study found that people with learning disabilities have This 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).  | Dissemin-ating |
| Oral health of adults with learning disabilities and its determinants<https://www.sldo.ac.uk/projects/health/oral-health/> | Large, 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.  | In progress |
| Understanding the levels and inter-relationships of dental and medical complexity in adults with learning disabilities<https://www.sldo.ac.uk/projects/health/oral-health/> | Secondary analysis and record linkage using LES 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.  | Approval sought |
| A decade of psychotropic prescribing for adults with learning disabilities <https://www.sldo.ac.uk/projects/health/psychotropic-prescribing/>  | Analysis of trends in psychotropic prescribing over 10 years in a large 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 that their use is regularly reviewed and reduced. Preliminary results from this study suggest a slight decline in antipsychotic prescribing (most recent data still under analysis), with a marked increase in antidepressant prescribing. Supporting appropriate prescribing is aligned with the strategic direction of *The Keys To Life.* This study will feedback trends to prescribers, helping them to meet good practice targets. | In progress |
| Prescribing trends in children and young people with learning disabilities, and in children and young people with autism<https://www.sldo.ac.uk/projects/health/psychotropic-prescribing/> | Record linkage of Scotland’s Pupil Census with Scottish Morbidity Record 01 and 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. | Approval being sought |
| Children and young people with learning disabilities and children and young people with autism in Scottish schools<https://www.sldo.ac.uk/projects/children-young-people/pupil-census/> | 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. | In progress |
| Hospital admissions for physical conditions for people with learning disabilities<https://www.sldo.ac.uk/projects/secondary-healthcare/hospital-admissions/>  | 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. | Dissemin-ating |
| Quality of health care in children and young people with learning disabilities, and in children and young people with autism<https://www.sldo.ac.uk/projects/secondary-healthcare/hospital-admissions/> | Record linkage of Scotland’s Pupil Census with Scottish Morbidity Record 01 and Prescribing Information System | 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 a indicator of trends in health care quality over time for policy-makers. | In progress |
| Life expectancy and causes of death of people with learning disabilities<https://www.sldo.ac.uk/projects/mortality/life-expectancy/> | Systematic review  | This study has 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 than do men with learning disabilities). This requires further study, and work to support policy-makers. | Dissemin-ating |
| Causes of death in children and young people with learning disabilities and children and young people with autism<https://www.sldo.ac.uk/projects/mortality/life-expectancy/> | Record linkage of Scotland’s Pupil Census with National Records of Scotland death records | 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. | In progress |
| Life expectancy and causes of death of people with Down syndrome<https://www.sldo.ac.uk/projects/mortality/life-expectancy/> | Systematic review  | This study will provide information about how life expectancy and causes of death of people with Down syndrome differs to the general population, and the trends over time. Changes in lifespan are important to quantify, given the high levels of dementia in over 50 year olds with Down syndrome. This will help in planning services and resources to support this ageing population. | In progress |
| Trends in infant mortality and childhood survival in children with Down syndrome | Regional genetics unit data linked to CHI, NRS death records, and Scottish Morbidity Record 01 | 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 advances in surgery and access to surgery. We will also relate this to 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. | In progress |
| The physical and mental health of people with comorbid autism and learning disabilities in Scotland<https://www.sldo.ac.uk/projects/health/census-2011-people-with-learning-disabilities-autism/> | Analysis of health data from people with learning disabilities and autism compared with the general population using Scotland’s Census, 2011 | 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. | In progress |
| 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<https://www.sldo.ac.uk/projects/other-health-determinants/spending-on-services/> | Secondary analysis of data from Information Services Division and NHS National Services Scotland | Any variation will be interpreted through “case” work to understand different population needs and third sector provisions in localities. Services are changing, and this may impact on trends in expenditure, which will be bench-marked against trends in expenditure for other care groups. This work may provide information to support service planning and design across Scotland. | In progress |
| Mental health and learning disabilities inpatient census 2014 & 2016: Patients with learning disabilities aged 18 and older<https://www.sldo.ac.uk/projects/secondary-healthcare/inpatient-bed-census/> | 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. | In progress |
| Changes in living circumstances and impact on health of young people and adults with learning disabilities and young people and adults with autism 1991-2011<https://www.sldo.ac.uk/projects/other-health-determinants/living-circumstances-and-health/> | Secondary analysis using data from the Scottish Longitudinal Survey  | This study will assess the residential mobility, and types of residence, of people with learning disabilities and people with autism compared with the general population, and its associations with health. There have been considerable changes in policy for people with learning disabilities, and a greater awareness and diagnosis of autism over this 20 year period. We do not know if household compositions and movement is associated with health in these populations, so at present cannot make recommendations on best practice and impact of policy changes. The introduction of self-directed support and health and social care integration may also have health outcomes, and this study provides baseline measures for further evaluation of this. | In progress |
| What is the effect of transition from school to adulthood on health and wellbeing in young people with learning disabilities?<https://www.sldo.ac.uk/projects/children-young-people/transition/> | 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. | Dissemin-ating |
| The impact of transition from school to adulthood on health and wellbeing in young people with learning disabilities<https://www.sldo.ac.uk/projects/children-young-people/transition/> | Secondary analysis of data from Scotland’s Census 2011, and a qualitative study | Both physical and mental health are poorer in young people with learning disabilities aged 16-24 than those without learning disabilities. 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. Further analysis is underway to identify areas that could be recommended to improve transition planning.  | In progress |
| Impact of hate crimes and targeted violence on health and wellbeing of people with learning disabilities<https://www.sldo.ac.uk/projects/other-health-determinants/hate-crime/> | Narrative review and qualitative study with people with learning disabilities, their families, carers, representatives from disabled people’s organisations, and Police Scotland  | Issues with police coding of hate crimes have been identified and reported. Themes will be identified and drawn together to identify the extent and impact of hate crimes.  | In progress |