

Scottish

Learning Disabilities

Observatory

December 2018

This e-newsletter from SLDO brings you all the exciting news on the latest work of the Observatory and on events that are coming up that may be of interest to you.

Welcome

Welcome to our last newsletter of 2018. In this issue we provide updates on existing projects and highlight new areas of work that are in the early stages of development. This year we have taken up opportunities to raise awareness amongst the public of some of the issues that people with learning disabilities experience in relation to their health and care. You can read about one of these events [here](#). We also welcome two new members of staff to the Observatory.

Calendars are already filling up quickly for 2019 and we look forward to the forthcoming learning disabilities strategy update, which will reflect on the many achievements since the publication of The keys to life in 2013, and provide a vision for the next stage of policy priorities. We continue to work closely with the Scottish Government policy team and with other partners across the sector to ensure that the Observatory's work is aligned with policy and practice.

We are very excited about welcoming the global intellectual disabilities community to Glasgow in August to attend the [IASSID World Congress](#). Over 1,200 people are expected to attend this meeting, which will cover a wide range of topics from ageing, communication, parenting, inclusive education to physical health.

I hope you enjoy getting up to date on our work and as always, we invite you to get in touch if you want more information. In the meantime have a wonderful festive season and I look forward to seeing you in the new year!

Project Updates

The oral health of adults with learning disabilities

Oral health care is a fundamental part of personal care, and a priority for the World Health Organisation and the Scottish Government. Adults with learning disabilities experience extensive health inequalities, yet their oral health has largely been

overlooked. To address this gap in evidence the Observatory is looking at the oral health of people with learning disabilities.

We have carried out oral health checks on 560 adults with learning disabilities and found that 31% had no teeth; this is more than double the rate of the general population (15.1%). We also found that 42% of the population with learning disabilities had less than 21 teeth which we know can impact negatively on confidence, being able to eat, speak and may also contribute to choking, which is emerging as one of the most common causes of deaths in people with learning disabilities. Read about the project [here](#).

In another project, we will be linking electronic patient data to further investigate the extent of dental problems in this population. You can find out more on this project in this [short video](#).

Health conditions in people with autism

We have recently published three reports on health conditions in people with autism identified through [Scotland's Census 2011](#).

In the first of these reports, we found that children and young people with autism were more likely to experience hearing loss, sight loss, physical disability, mental health problems and to have learning disabilities when compared to other children. Girls with autism experienced more health problems than boys with autism. If you want to know more, watch this [video abstract](#) or read the [full report](#).

The second report focussed on adults with autism, who were 95 times more likely to have learning disabilities than other people. Adults with autism were also significantly more likely to experience mental health conditions, blindness or partial sight loss, physical disability, and deafness or partial hearing loss than other people. If you want to know more, watch this [video abstract](#) or read the [full report](#).

The final report investigated the health of those with both learning disabilities and autism. This group of people was 49 times more likely to have poor health. The great majority also experienced more limitations in their day-to-day activities due to health problems. Children and young people were particularly affected by these inequalities, with 77.4% of them reporting severe limitations to their daily lives. [Click here to read the full report](#).

Engender

Dr Phillippa Wiseman at the Observatory and Dr Jo Ferrie, University of Glasgow, have been working in collaboration with disabled women and Engender Scotland on a project exploring the reproductive rights of disabled women in Scotland. The Observatory undertook focus groups with women with learning disabilities and collaborated in the design of an easy read survey to include women with learning

disabilities. The project uncovered significant inequalities experienced by women with learning disabilities in relation to their reproductive and maternal health and wellbeing. More information about the project and its findings can be accessed through the project [here](#).

New staff at the Observatory

Gillian Smith has recently joined the Observatory as a research assistant. She is currently working in the observatory on a project investigating health and educational outcomes for children and young people who have learning disabilities or autism, including those prescribed antipsychotic drugs.

Rhiann McLean has joined the Observatory as Public Engagement Lead. She will work on a new project called Research Voices funded by the Wellcome Trust to develop and evaluate an approach to inclusive health research with people with learning disabilities.

New projects

Research voices: including people with learning disabilities in health research

People with learning disabilities are often excluded from health research and their views are rarely captured in all stages of the research process. The Observatory has recently been awarded funding from the Wellcome Trust Public Engagement Fund to develop and evaluate an approach to inclusive health research with people with learning disabilities. The aim of this project is enable deliberation on health research and to challenge barriers and attitudes that exclude people with learning disabilities either as subjects or participants in studies. Read more about the project [here](#).

Parents with learning disabilities

Parents with learning disabilities are a priority in Scotland's national learning disabilities strategy. The planning and delivery of effective policies and supports for this group require accurate information on the number of parents with learning disabilities in Scotland. This project will address current gaps in the evidence by linking data from Scotland's Census 2011 with maternity, birth and other routinely collected records to investigate the prevalence parents with learning disabilities, as well as health and care outcomes of mothers with learning disabilities and their children. Read more about the project [here](#).

Down Syndrome Cross Country Collaboration Project in Scotland & Wales

We are currently working with colleagues at Cardiff University to compare mortality rates and hospital admissions (2003-2012) in children with and without Downs syndrome up to the age of five in Scotland and Wales. This project will allow us to

investigate if improvements in healthcare and attitudes have impacted on survival trends, and compare findings across Scotland and Wales. More information about this project can be viewed [here](#).

Educational and health outcomes in children and young people with autism and/or learning disabilities, using Scotland's Pupil Census:

Children and young people with learning disabilities and/or autism spectrum disorders have poorer overall health than the equivalent general population. We will use Scotland's Pupil Census to identify children with learning disabilities and/or autism, anonymously. We have linked this information with routinely collected health information, to investigate child educational outcomes as well as adverse health events, including for those prescribed antipsychotic drugs.

Public Engagement

Curiosity Live at the Glasgow Science Centre; a collaboration with the Scottish Learning Disabilities Observatory and People First

On the 9-11th of November 2018 we took part in Glasgow Science Centre's Curiosity Live event celebrating research, innovation and creativity going on in Glasgow and across Scotland.

Team members of the Scottish Learning Disabilities and People First attended this exciting and interactive venue for their first collaboration on a co-designed public engagement activity about the health and lives of people with learning disabilities in Scotland. We developed a game that involved players progressing around a board that represents the key aspects of a person's life: going to school, going to university, going to work, making friends, for example. The cards and the 'life encounters' on the game were based both on the research findings that we have collected at the Scottish Learning Disabilities Observatory or real experiences of people with learning disabilities informed by People First members.

The collaboration with Scottish Learning Disabilities Observatory and People First was a very valuable experience and we believe the activity was greatly enriched by children, young people and adults being able to hear about the lived experiences of a person with a learning disability.

Read about event [here](#).

Events

[Scotland's National Learning Disability Week](#)

From Monday 13th May – Sunday 19th May

[IASSID World Congress](#)

Glasgow, 6th - 9th August 2019

Alternative formats

If you require documents in an alternative format such as hard copy or easy read, please contact us at sldo-info@glasgow.ac.uk or call us on 0141 211 3908