

May 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

You will all know that today is the start of Scotland's Learning Disabilities Week. To celebrate this we will be posting updates on 7 projects over the next 7 days via twitter (#LDWeek2018).

It has been a busy year here at the Observatory. Several of our key projects have now produced results, and a number of new projects are starting. We are thinking about how we communicate our findings to different audiences and how to engage better with people with learning disabilities. We will start an exciting new project to work with people with learning disabilities to produce a report and recommendations on the inclusion of people with learning disabilities in health and health care research. Information on the project will be posted on our website very soon.

We are involved in the plans for the next <u>International Association for the Scientific</u> <u>Study of Intellectual and Developmental Studies</u> World Congress to be held in Glasgow in 2019. This event, which happens every 3 years, brings together researchers, clinicians, policy makers, self-advocates and carers from every corner of the world. We will be sure to keep you informed of developments and opportunities to get involved.

And one final note, new European legislation <u>GDPR</u> comes into force this month on data protection. This means that we must contact everyone on our database to ask for permission to retain contact information. If you would like to be kept informed of Observatory events and updates on our work please take 5 minutes to respond, or simply go to our website <u>www.sldo.ac.uk</u> and enter your details at the bottom of our home page.

We look forward to another exciting and productive year!

Anna Cooper, Director, Scottish Learning Disabilities Observatory

New Publications

We have seen the publication of a number of papers from our wide ranging projects in high quality peer reviewed journals.

Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: cross-sectional study http://eprints.gla.ac.uk/149247/

Early death and causes of death of people with Down syndrome: A systematic review <u>https://onlinelibrary.wiley.com/doi/full/10.1111/jar.12446</u>

The relationship between physical ill-health and mental ill-health in adults with intellectual disabilities http://eprints.gla.ac.uk/159234/

New projects

Disabled Women: Our Bodies, Our Rights

The Scottish Learning Disabilities Observatory will be collaborating with Engender Scotland to make the voices of disabled women more visible in sexual health, reproductive experiences and sexualities discourses. As part of this project we will be holding focus groups with women with learning disabilities to explore their experiences of making choices around their sexual and reproductive health in order to make visible the inequalities that they face.

As Engender note 'We want to tell service providers what works well and what needs to be improved. We want to find out more about disabled women's experiences of services around having or not having children. We are interested in disabled women and girls experiences of sex education, support with menstruation, access to family planning advice and contraception, maternity and parenting services'.

We will be updating our website as the project progresses.

You can find the link to the 'Disabled Women: Our Bodies, Our Rights' survey at <u>https://www.surveymonkey.co.uk/r/HKJ2R8N</u>

For more information please contact Dr Phillippa Wiseman at Phillippa.Wiseman@glasgow.ac.uk or 0141 330 4548

Older parent carers health and its reciprocal effect on their ageing offspring with learning disabilities

The Scottish Learning Disabilities Observatory has recently been awarded funding by The Baily Thomas Charitable Fund to investigate the health of older parent carers and their ageing offspring with learning disabilities. The proposed study addresses important and overdue questions on health and health care of older parent carers with a son or daughter with learning disabilities.

The project is due to start in October 2018 and information about the project will be on our website soon. We will also be advertising for a Research Assistant for this post in the coming months. For more information on this project, please contact <u>Deborah.Kinnear@glasgow.ac.uk</u>

New data

There are over 21,000 adults with learning disabilities in Scotland. We investigated changes in expenditure on adult learning disabilities health and social care services in 2012/13, 2013/14 and 2014/15 and presented a breakdown of this data on our website. Follow this link to explore changes in expenditure in your local authority area. https://www.sldo.ac.uk/census-2011-information/expenditure-on-adult-learning-disabilities-services/

Staff Vacancy

We are currently recruiting for a new research assistant to conduct a programme of research, public engagement and knowledge exchange. This new post will contribute to raising awareness of, and providing evidence-based solutions to the very poor health and health inequalities currently experienced by people with learning disabilities. Further details can be found on the University of Glasgow website. https://www.gla.ac.uk

Events

Scotland's National Learning Disability Week Monday 14th - Sunday 20th May 2018

NHS Scotland Event, SEC, Glasgow 18th - 19th June 2018 IASSID Europe Congress

Athens, 18th - 20th July 2018

World Down Syndrome Congress Glasgow 25th - 27th July 2018

Lancaster Disabilities Study Conference Lancaster, 11th - 13th September 2018

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