



Scottish Learning Disabilities Observatory

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Scottish Learning Disabilities Observatory Newsletter Volume 4, May 2017

Scottish

Learning Disabilities

Observatory



May 2017

Welcome from the Director

Tackling the persistent inequalities experienced by people with learning disabilities continues to be a major priority for the Scottish Government. This can only be built on a solid foundation of good quality evidence. This need is recognised by United Nations Committee on the Rights of Persons with Disabilities in their recent request to UK Governments to provide information on:

How health inequalities for persons with disabilities, in particular persons with psychosocial or intellectual impairments, are monitored and eliminated

Over the last 2 years the Observatory has worked with data providers to enable us to gain access to information about the health and care of people with learning disabilities across domains of life and at all stages of the health and care journey in order to build the foundations for action to achieve health equality.

Scotland's Census 2011, provides one of the richest sources of information about the lives of people with learning disabilities and their carers. Completed by 97% of the whole population this data is probably unique in the world. We have worked with National Records of Scotland to ensure this information is presented in a useful and accessible way to enable practitioners and people responsible for designing and delivering services to have a better picture of the lives of people with learning disabilities and people with autism in Scotland.

Information gathered by institutions providing public services is also vital in monitoring health and health care for people in these populations and through linkage across these routinely collected information sources we have been able to explore trends in psychotropic drug prescribing, health and health care management in primary care, use of inpatient mental health and learning disabilities beds and physical health.

We have gained permission from the NHS and the Scottish Government to undertake a comprehensive, longitudinal analysis of the health and health care of children and young people in Scotland with learning disabilities and with autism. By linking Scottish education data with health information we will analyse and compare trends in the health and health care experienced by all children and young people in Scotland. Check out our website for progress on this important work. (www.sldo.ac.uk)

The mental health and wellbeing of people with learning disabilities is in the spotlight in this edition of our newsletter which follows hot on the heels of Scotland's Strategy for Mental Health and the new NICE guidelines on supporting people with learning disabilities and mental health problems. The Principal medical officer and psychiatric adviser to Scottish Government, Dr John Mitchell, has provided an article describing the new 10 year vision for mental health in Scotland and I have provided a short overview of the new NICE guidelines. We also welcome the contribution from Gillian Barclay who is the New Strategic Lead for Dementia, Autism and Learning Disabilities in the Scottish Government and look forward to working closely with Gillian in the future to develop the Observatory programme. As usual we also have updates from the Observatory work including articles on Psychotropic prescribing, psychosis and an update on our latest census analyses.

Publication of this issue will coincide with Scotland's national Learning Disability Week (15th-21st of May) organised by the Scottish Commission for Learning Disability. We hope that many of our readers will be joining us on the 16th of May at our second national conference to reflect on achievements and to help identify priorities towards realising greater equality for people with learning disabilities, people with autism and their families. Check out SCLD's website for information on all the activities taking place during learning disabilities week and to find out how you can get involved with #LDWeek2017.

As always we welcome the chance to collaborate and listen to those that are interested in our work so please do get in touch with us!

Anna Cooper

Professor Sally-Ann Cooper



Scotland's Census 2011: new data released!

By Angela Henderson and Laura Hughes-McCormack

Through our ongoing collaboration with National Records of Scotland and the Scottish Government we have analysed data on the lives of people with learning disabilities in Scotland in 2011.

In our latest analysis of this data we looked at households where people with learning disabilities lived to find out more about the composition of families and to identify the presence of family carers within these households.

In 2011 there were 26,300 people with a learning disability in Scotland and of these 87.4% lived in a private household. 54.7% of people who did not have learning disabilities but who lived in the same household as a person with learning disabilities described themselves as carers compared with only 9.2% of people living in households where there were no residents with learning disabilities.

Of the population of people with learning disabilities, 12,237 (46.4%) were living with their families; 7,478 (61.1%) were living with both parents

and 4,759 (38.9%) with one parent only. In comparison, 1,437,403 (27.1%) of people without learning disabilities were found to be living with parents; 1,004,329 (69.9%) were living with both parents and 433,074 (30.1%) with one parent only. Of the total population, excluding people with learning disabilities, 488,962 people reported being family carers (or providing unpaid care in private accommodation); 18,494 (3.8%) were living with a person with learning disabilities, in comparison to 15,250 (0.3%) of people who were not carers.

This new batch of analyses also provided information on levels of deprivation across the domains of employment, education, health or housing. Scotland's Census 2011 defines 'deprived households' as those that meet the following conditions:

- A person in the household aged 16 or over, who is not in full-time study and is either unemployed or long-term sick or disabled;

- There is no person aged 16-64 in the household whose highest level of education is level 2 or above, or no person aged 16-18 is a full-time student;
- Any person in the household has 'bad' or 'very bad' general health, or has a long-term limiting health problem or disability; and/or
- The household's accommodation is either overcrowded, is in a shared dwelling or does not have central heating.

Our analysis found that only 2.6% where not experiencing deprivation in at least one of these areas. This compares to 45.7% for those without learning disabilities.

We will be conducting further analyses and interpretation of these data over the next few months – check on our website for the latest data. www.sldo.ac.uk



Get involved!

Take a photo of yourself posing with Learning Disability Week flags at landmarks across the country.

People can either email the photos to The Scottish Commission for Learning Disability, or use #LDWeek2017 in their social media posts to help us to see and share them.

10 years of anti-psychotic prescribing in Scotland

Angela Henderson

Deputy Director of the Scottish Learning Disabilities Observatory



Background and aims

The rate of anti-psychotic drugs prescribed to people with learning disabilities does not correlate with reported rates of psychosis. There is strong evidence that in many cases, anti-psychotic medications are used to manage 'problem behaviours'. However these drugs are not licensed for use in this context and more importantly their effectiveness in behavioural management beyond sedation has not been evidenced. At the same time these medications are known to have significant side-effects.

Methods

A representative sample of 1,201 adults with learning disabilities had individual mental and physical health and drug assessments in 2004 and 2006.

In 2014, drug information was extracted from GP records for all 4,065 adults with learning disabilities living in Greater Glasgow and Clyde.

Of the original 1,201 adults with learning disabilities, drug data was available following record linkage to Scotland's national records of all encashed prescriptions (Prescribing Information System). We were able to link information for 368 of the adults from 2004, 2006 and 2014.

Findings

In 2004, of the 1,201 adults, 292(24.3%) were prescribed an antipsychotic, despite only 4.4% having psychosis. Two years later in 2006, of the 648 adults, 130(20.1%) were prescribed an antipsychotic drug. In 2014, for the whole population of 4,065 adults, a lower proportion of 665(16.4%) were prescribed antipsychotic drugs (Graph 1).

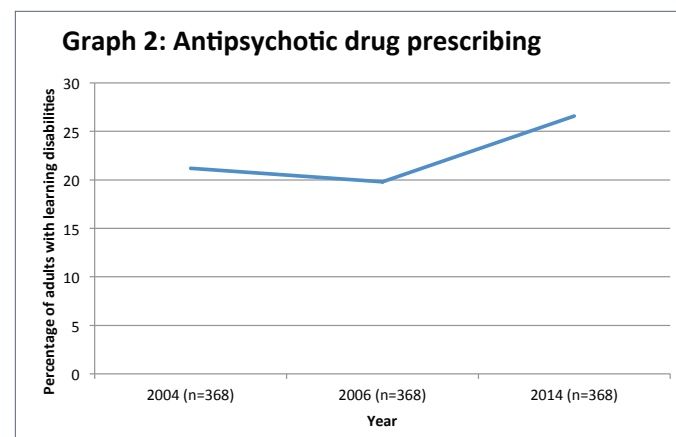
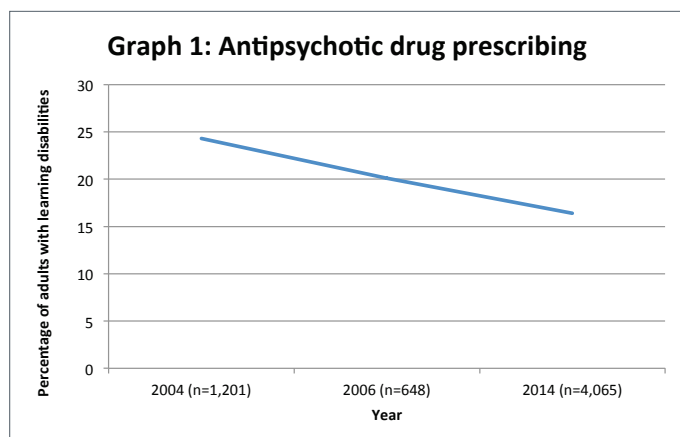
However, tracking the same individuals (n=368) in 2004, 2006 and in 2014 revealed that 78(21.2%) were prescribed antipsychotics in 2004, 73(19.8%) in 2006, and 98(26.6%) in 2014 (Graph 2).

Conclusions

In the population of adults with learning disabilities antipsychotic drugs are prescribed at much higher rates than there are people with psychosis. Overall the rate of prescribing of antipsychotics appears to have fallen for the whole population with learning disabilities between 2004 and 2014. However for those individuals originally on antipsychotics in 2004 these prescriptions were not withdrawn. These findings suggest that the rate of newly instigated prescriptions of antipsychotic medications are declining, albeit to rates that are still significantly higher than the rate of psychosis in the population. Crucially though the study shows that once a prescription for an antipsychotic medication has been initiated it is unlikely that this will be withdrawn.

Implications for policy and practice

Concerted action to reduce antipsychotic prescribing must be taken to ensure that all adults with learning disabilities have access to the highest quality, evidence informed health and health care. This demands regular medication reviews and proactive steps to reduce or withdraw antipsychotic medications for people with learning disabilities who do not have psychosis.



Management of serious mental ill-health among people with learning disabilities in primary care: a comparison over time

by Laura Hughes-McCormack

Research Assistant, Scottish Learning Disabilities Observatory



Why is this project important?

Mental ill-health is unevenly distributed across the population, and appears to be more prevalent among people with learning disabilities compared with the general population. Little is known about the quality of health care provided to people with learning disabilities who have mental ill-health.

We investigated the management of long term conditions, including serious mental ill-health, specifically psychosis, in primary care among adults with learning disabilities at two time points (2007 and 2014), compared with the general population.

Where did this information come from?

We analysed primary care data from practices in NHS Greater Glasgow and Clyde where a learning disabilities Enhanced Service was implemented in 2012 to improve the quality of primary health care for adults with learning disabilities. This enhanced service included identification of the population with learning disabilities aged 18 and over, in an annually updated register; a programme of nurse-delivered primary care health checks, coordinated by the learning disabilities primary care liaison team; and support to general practices provided by the learning disabilities primary care liaison team. We analysed health and health care indicators for adults with learning disabilities compared with the general population between 2007 and 2014 in NHS Greater Glasgow and Clyde.

What did we find?

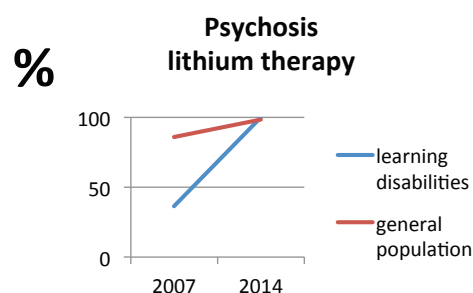
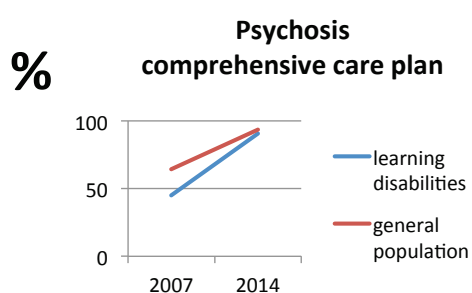
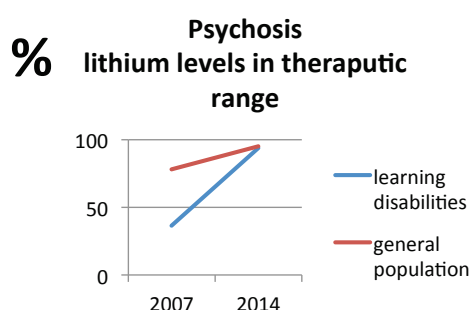
For the management of psychosis in 2007, adults with learning disabilities received poorer care on 4/4 (100%) of the indicators measured. This difference was statistically significant for 2/4 (50%) indicators. In 2014, there was still a disparity in achievement of good practice indicators where 5/9 (55.6%) were found to be poorer for the population with learning disabilities when compared to the general population. This difference was statistically significant for one indicator. This analysis reveals that care for adults with psychosis had improved between 2007 and 2014, for both the learning disabilities population and the general population. The rate of improvement was greater for the learning disabilities population. Notably, where direct comparisons were possible in the data, health care had improved across all of the psychosis care indicators (see graphs).

What are the implications of this study?

This analysis shows that for all adults with psychosis there have been significant improvements in primary care. Whilst health care inequalities still exist, NHS Greater Glasgow and Clyde has effected a step-change in the care of adults with learning disabilities and psychosis which resulted in a reduction in the health-care inequality gap across the period studied. These findings suggest that routine monitoring of primary care data can improve understanding of the factors driving change and improvement at a local level.

The remaining inequalities highlight that greater awareness and further action is still necessary to achieve equality for adults with learning disabilities. However the progress reported in this study should be shared across other health board areas to support improvement at a national level.

For more information, please contact Laura at: Laura.Hughes-McCormack@glasgow.ac.uk or visit www.sldo.ac.uk



Mental Health in Scotland: a 10 year vision

Dr John Mitchell

Principal medical officer and psychiatric adviser to Scottish Government



Mental Health in Scotland

Mental health in Scotland is currently under the spotlight with the publication of Scotland's 10 year vision for mental health. The new strategy refreshes and updates the Scottish Government's vision for mental health improvement that was set out in 2012. Whilst significant progress has been made since 2012 important challenges remain. The new strategy has been subject to considerable consultation across Scotland, a process which has generated an unprecedented number of responses indicating the importance of this area of policy to a diverse range of stakeholders, including people with learning disabilities and their families. The analysis of these responses is published here:

www.gov.scot/publications/2016/12/1634

What has been proposed?

At the heart of the strategy is the drive to ensure 'parity of esteem' for mental and physical health in order to achieve the best possible mental health outcomes at all levels of the health service; for people across the lifespan; and across the service boundaries.

Early actions and expected outcomes have been defined over the following themes:

- Prevention and early intervention
- Access to treatment and joined-up, accessible services
- The physical wellbeing of people with mental health problems
- Rights, information use and planning
- Data and measurement

The proposals have been deliberately designed to incorporate targeted action to improve mental health and wellbeing outcomes in all population groups, including people with learning disabilities.

Mental ill-health is not evenly distributed across the population and adults with learning disabilities have the highest rates of mental ill-health of any group in society, with a point prevalence of mental ill-health at 41%. This is much higher than for the general population, and we recognise it is critical that we take

action to address this inequality. People with learning disabilities also have poorer physical health and more physical health conditions / multimorbidity than the general population, and experience barriers in accessing appropriate health care.

In developing the mental health strategy for Scotland, we have sought to lead the way in outlining a set of evidence based proposals that tackle the mental health and care inequalities that people with learning disabilities of all ages experience. We recognise there is an essential step of identifying and implementing the adjustments that need to be made at a policy and programme level to ensure these will not maintain or create further inequality, so that the intended improvements are achieved for all of Scotland's people.

High quality evidence still needs to be further developed to inform policy makers, commissioners and practitioners about the specific actions that will be required to improve the mental health of people with learning disabilities. Organisations, like the Scottish Learning Disabilities Observatory have a critical role to play in ensuring that this evidence is available to support delivery of the strategy's vision over the next 10 years.

Read Scotland's Strategy for Mental Health here:

www.gov.scot/esource/0051/00516047.pdf

New NICE guidelines on supporting people with learning disabilities and mental health problems

By Professor Sally-Ann Cooper

It is shocking how little we know about the mental health problems of people with learning disabilities.

A new clinical guideline published by the National Institute of Health and Care Excellence (NICE) shows mental ill-health is a big problem for people with learning disabilities, but research on it is severely limited. This means mental health needs are often overlooked and left untreated.

NICE provides evidence-based guidance and advice to improve health and social care. The new guideline is a thorough and important document outlining what we do and don't know. Among the 382 pages of evidence the guideline group compiled, are important recommendations to help improve mental health outcomes for people with learning disabilities. The guideline also points out that we need much more research to help people with learning disabilities.

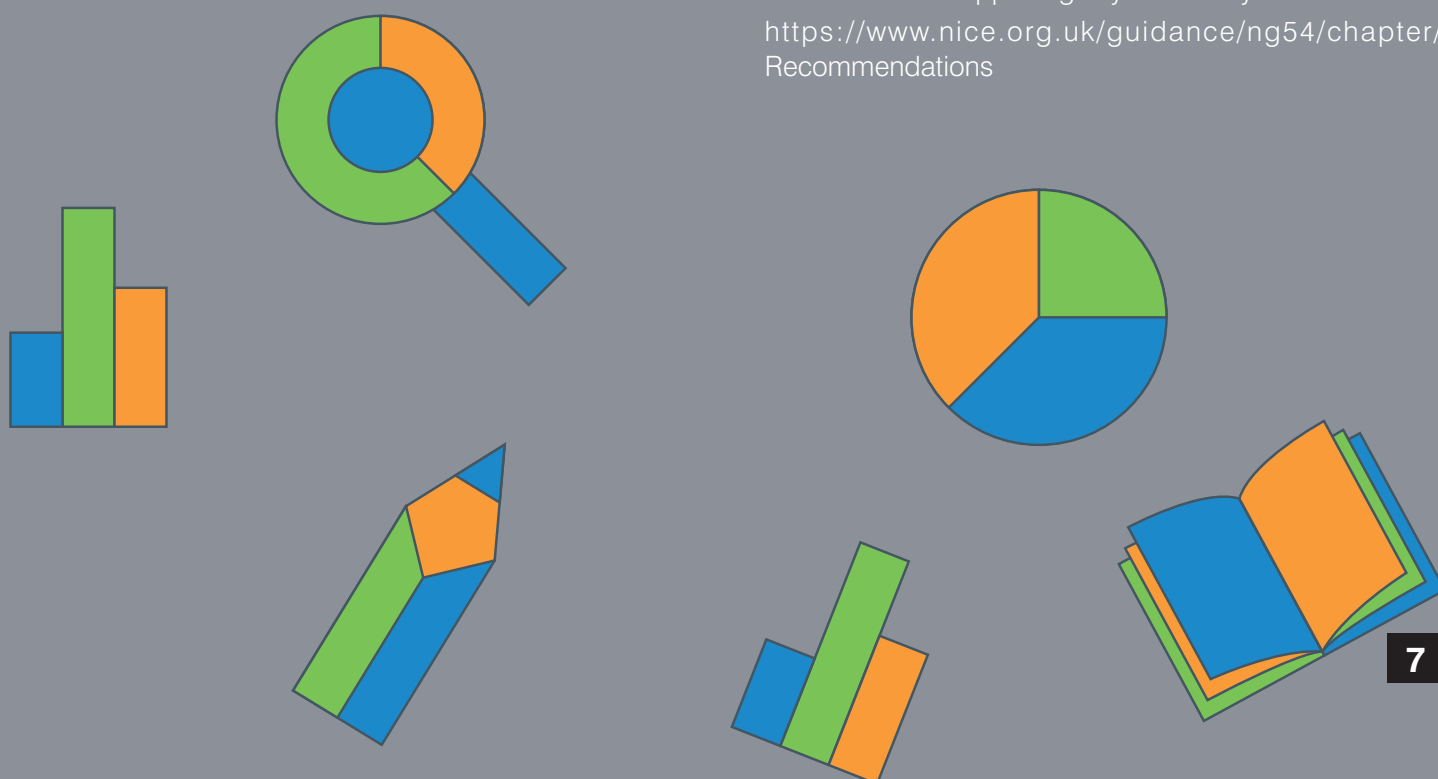
The Department of Health, England, and the Welsh Assembly asked NICE to prepare the clinical guideline in recognition that for people with learning disabilities, mental health problems are too frequently overlooked or misattributed. This has meant that some people with learning disabilities aren't getting the right treatments when they need them, or get the wrong treatments. Poor access to services and variability in service provision often makes matters worse.

The guideline is an important step forward, and could make a real difference to the lives of people with learning disabilities. NICE guidance is officially for England, but there are agreements to provide some NICE products and services to Scotland. Here is a taste of some of the recommendations.

- All people with learning disabilities and a serious mental illness should have a key worker.
- Health, social care, and education services should train all staff who may come into contact with people with learning disabilities to be aware about their mental health problems. (This recommendation is for all staff, not just those working in learning disabilities services.)
- Health, social care, and education services should support people to live where and with whom they want.
- People with learning disabilities should be offered an annual health check by GP practices.
- Parent training programmes specifically designed for parents or carers of children with learning disabilities should be considered to prevent or treat mental health problems in the child, and to support carer wellbeing.
- Family members and carers should be advised about their right to a formal assessment of their own needs and health, and their right to short breaks and respite care, and how to get them.

Read the recommendations – they are good practices that should be happening in your locality.

<https://www.nice.org.uk/guidance/ng54/chapter/Recommendations>



Who's Who?

Gillian Barclay

*Strategic Lead for Dementia, Autism and Learning Disabilities
Health and Social Care Integration, The Scottish Government*



Describe yourself in three words.

Open, Flexible, Reflective

Can you tell us a little bit about your career up to this point?

I worked for 10 years in the private sector before coming into public service, first in South Ayrshire Council Social Work, then Local Government Finance in the Scottish Executive. I moved into my first policy role in 2004, as head of fisheries quota and markets policy, before moving into food and drink policy. I moved across to the Health Directorate in 2009 as Head of Older People's Care. I had a career break in 2014/15 and came back to lead on dementia policy in 2015. Autism and Learning disabilities were added to my portfolio in March 2017.

Could you tell us a bit about your current role?

I am looking forward to setting out the strategic priorities for Learning Disabilities and Autism for the next three years as part of refreshing the strategic outcomes for the Keys to Life implementation and the National

Autism Strategy over the next few months. We are also just about to publish the third three year strategy for dementia in May. I also co-ordinate a European Joint Action on Dementia which is focussed on international action to improve the lives of people living with dementia and their carers across Europe. This means I get to travel occasionally to visit examples of excellent dementia care practice in other countries, which is a great honour. I can already see several linkages with the work on Learning Disabilities in terms of dementia friendly communities and social interventions and care pathways.

Where does learning disabilities policy fit with your role?

Learning Disabilities Policy is one of the three key Scottish policies I will be working with Scottish Ministers and stakeholders on for the next few years. I only started taking responsibility for this area in March 2017, but I am already impressed by the passion and commitment of the people I've met who are trying to make Scotland a more inclusive and open minded society.

What book should every policy maker read?

John Rawls "A theory of Justice"

What motivates you on a daily basis?

Seeing the impact that good policies can have on the lives of people.

What has been the most rewarding aspect of your career so far?

Being lucky to meet with some extremely inspirational entrepreneurs and social reformers – not just leaders, but carers and advocates and others who just care about people, the environment we live in, and the future of our society. I really can't believe my luck sometimes.

How do you achieve a work/life balance?

In 2014 I lost my 18 year old son Cameron Lancaster in a tragic accident in a quarry in Fife. On returning to work, I found that my motivations and priorities are quite different to my view of life before the loss. I try to spend a couple of days a month working on water safety issues on the Scottish Water Safety Forum and have helped to write Scotland's first draft Drowning Prevention Strategy. I speak to high school pupils all round Scotland about the dangers of open water and the long term impacts of the loss of a young life. This work brings me into contact with all the rescue and protection agencies and gives me a different perspective on risk taking and risk management. I have three other children who are mostly grown up. We also have a puppy and a cat – so I guess they all keep me grounded (in the kitchen mostly!).

News and reviews

Below are some events that you may be interested in.



Scotland's first national learning disability awards

Date: 19 May 2017

Venue: Grand Central Hotel in Glasgow

The Scottish Commission for Learning Disability has launched Scotland's first national Learning Disability Awards. The awards aim to highlight, at a national level, the rarely heard stories and achievements of people with learning disabilities and the people who support them. The awards ceremony forms part of a wide range of events being held to mark Learning Disability Week 2017, a platform to make visible those who are excelling in areas where people with learning disabilities are rarely represented.

Find out what is happening across Scotland during Learning Disability Week (15th-21st May 2017) by visiting the SCLD webpage: <https://www.sclد.org.uk/learning-disability-week-events>



Health Issues SIRG 2017 Conference

Date: 19-21 June 2017

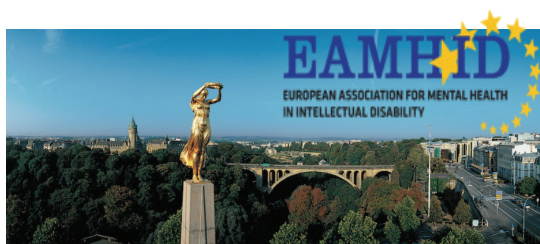
Venue: Hilton hotel in Belfast

Bridging the gap: from evidence to improved health for persons with intellectual and developmental disabilities



World Down Syndrome Congress 2018

July 2018 – Glasgow will be hosting the World Down Syndrome Congress. Over 1,300 people will attend the Scottish Event Campus over four days, with workshops, meet the expert sessions, presentations and talks by people with Down syndrome, people working with them and by researchers and medics. In total over 100 sessions to choose from.



11th Congress of the European Association for Mental Health in Intellectual Disability (EAMHID 2017)

Date: 21 - 23 September 2017, Luxembourg

News and Reviews

New PhD Student



Kirsty has been working for the Scottish Learning Disabilities Observatory as a research assistant since 2015 and has recently started a PhD. Her PhD will examine the mental health of fathers who care for their son or daughter with learning disabilities. This project is important as more fathers are now taking an active caregiving role and yet there is very little research in this area. We need to find out more about the mental health of father carers and their experiences of support services. This may inform service providers and policy makers about how they can better support fathers.

By conducting analysis of Scotland's Census 2011, Kirsty will find out about father carers' mental health and what factors are associated

with poor mental health. The Census will allow her to identify the whole population of father carers in Scotland, making this study unique. Kirsty will also conduct interviews with father carers to learn more about their experiences of caring for their son or daughter with learning disabilities.

This study will increase our understanding of the mental health of father carers living in Scotland, ensuring that they can be provided with the right information and the right support, which will be beneficial not only to them but also to the care they provide for their son or daughter.

For more information email:
k.dunn.1@research.gla.ac.uk



Welcome to Marian

Marian Okon joined the Scottish Learning Disabilities Observatory in October, 2016 as a part-time researcher. Prior to this role, she worked as a biomedical scientist/public health scientist for five years on various research projects including behavioural studies on alcohol and environmental health research.

She is interested in research that relates specifically to promoting healthy living in people with learning disabilities. She is currently working on two projects in the observatory, which will investigate:

The trends in antipsychotic prescribing in children and young people with autism and/or learning disabilities in Scotland, between 2009 and 2015

The trends in per capita spending by individual health boards (or local authorities) for 2012/13, 2013/14 and 2014/15 on learning disability services for adults in Scotland

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