

## Welcome from the Director

*I hope you like this first edition of our newsletter!*

The Scottish Learning Disabilities Observatory is here to provide the evidence practitioners and policy-makers need to tackle the health inequalities experienced by people with learning disabilities, and people with autism. This is to make Scotland fairer and healthier for people with learning disabilities, people with autism, and their families.

The Observatory team will find out about the health problems people have, its causes, and how good or bad health care is. We will then be able to find ways to make health, and healthcare better. This will help the government, and staff who organise and provide health and social services, to get it right for people with learning disabilities and people with autism. We will check if health gets better over time.

Evidence is very important—without it we cannot understand why inequalities exist, nor how to tackle them most effectively. That is why the Government has set up the Scottish Learning Disabilities Observatory.

Please tell us what you think. Over the coming months our team will be contacting people and organisations to ensure that we are focused on the work that is relevant to the lives of people with learning disabilities and people with autism living in Scotland today. Please get in touch if you want to find out more.

## Message from the Deputy Director

The Scottish Learning Disabilities Observatory has been set a challenging mission; to contribute to health improvement for people with learning disabilities by increasing the availability of relevant, high quality evidence that can inform policy and practice.

The Keys to Life made a call for urgent action to address the huge inequalities in health experienced by people with learning disabilities and underscored the importance of placing human rights at the centre of these actions.

It is right that there should be an explicit link between human rights and health. To make this approach a reality for the new Scottish Learning Disabilities Observatory means getting out and speaking to the experts. These experts are not just those who develop policies and deliver services – they are people with learning disabilities and their families. Effective engagement with people with learning disabilities and families will be vital if we are to integrate a human rights based approach into this work. It will ensure that we embed their knowledge, experience and priorities into a developing programme of work that is relevant and accessible.

This collaborative and inclusive approach also means that we will need to work across agencies and professions. We hope to champion the principles of equality, rights and justice and to reinforce the role they play in health improvement for people with learning disabilities in Scotland.

So, over the coming months we will be going out and about to meet people, to talk about what we are doing and what we hope to achieve through this work. But most importantly we will be listening to what people tell us. You can read about one of our first meetings, with The Good Life Group, on page 3.

If we get this right we have the opportunity to influence change, and make a real difference in the quality of life for people with learning disabilities in Scotland.

We hope you enjoy reading our first newsletter and welcome feedback. If you want to know more visit our website, email us or pick up the phone!



Professor Sally-Ann Cooper



Angela Henderson

## Meet the Observatory Team

### Dr Deborah Kinnear

Deborah is a Research Fellow. She is currently exploring a number of areas impacting on the lives of people with learning disabilities including: personalisation (self-directed support), physical health, oral health and carer burden.

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Email: Deborah.Kinnear@glasgow.ac.uk



### Laura Hughes-McCormack

Laura is a Research Assistant. She is working on a project looking at primary health care for people with learning disabilities in Scotland. The project focuses on reasons people with learning disabilities use primary care services and how their health is managed in these settings.

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### Dr Myrthe Jacobs

Myrthe is a Research Associate. She is currently working on a project on prenatal diagnosis for chromosomal conditions, such as Down syndrome. She is also looking at information on pupils with learning disabilities and with autism spectrum disorders in Scotland's schools.

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### Dr Ewelina Rydzewska

Ewelina is a Research Associate. She is investigating health needs, risks and inequalities for people with autism spectrum disorder. She is also analysing and visualising Scotland's Census data on people with developmental disorders and learning disabilities.

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### Kirsty Wright

Kirsty is a Research Assistant. She is currently synthesising evidence on secondary health care for people with learning disabilities. This project examines the reasons that people with learning disabilities are admitted to hospital, and how often.

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### Dr Lisa O'Leary

Lisa is a Research Assistant. She is currently synthesising evidence on the causes of death and life expectancy of people with learning disabilities.

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### Dr Phillippa Wiseman

Phillippa is a Research Assistant. She is currently exploring hate crime and targeted violence and the impact that harassment and violence has on the health and wellbeing of people with learning disabilities.

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### Heather Green

Heather is a part-time Administrative Assistant and the Observatory's first point of contact. She is ensuring our communication is fully accessible and also helps organise meetings and events.

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(Mondays, Thursdays and Fridays only)

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## SLDO Events

### *Meeting the 'Good Life Group'*

Deborah Kinnear and Angela Henderson  
Scottish Learning Disabilities Observatory  
University of Glasgow

On the 6th of May we were invited to attend a meeting with The Good Life Group to talk about the Scottish Learning Disabilities Observatory.

The Good Life Group was set up by people with learning disabilities with the support of a Local Area Coordinator. This group of self-advocates have been working across Scotland to change attitudes towards disabled people since 1999. Their work is mostly focused on providing training to health and social care professionals. Their contribution to improving the quality healthcare services for people with learning disabilities was recognized when the group won the COSLA Chair's Award for Excellence in Community Service in 2010.

The first question we asked the group was **what kind of things help people with learning disabilities to live a healthy life?**

A number of responses were provided which led to an in-depth discussion. Everyone agreed that **exercise** and **healthy eating** were central to healthy lifestyles. However they also recognised that this wasn't always easy to achieve and the group emphasised the importance of peer support. The group also talked about the different activities they were involved in, from Tai Chi to swimming and underwater cycling! Members of this group were very active and took part in lots of different activities. Many people talked about the importance of **good quality support** in accessing these opportunities. One member of the group also emphasized the importance of **oral health** as he had recently been involved in training sessions with dentists.

We were also interested in finding out about **positive experiences the group had of health and healthcare**. Some members of the group felt that they were often provided with **accessible information** and that health professionals did, at times, explain things clearly to them. The majority of the group said that they felt they could ask questions to health professionals if they ever felt they were unsure of anything. One member described an example of when she had received good support from care workers during a particularly difficult time in her life. Overall, there

appeared to be consensus that being kept informed and being supported were key to a good experience.

We also wanted to know if the group had **any experiences that were not so good?** Negative experiences included health and social care staff **speaking jargon** and using terminology which they found difficult to interpret. The group also reported **difficulty in understanding complicated instructions**. Two members of the group explained that the instructions for the bowel cancer screening test [for people over 50] were difficult to understand which subsequently led to confusion as to how to carry it out. Some of the group reported that health professionals often asked too many difficult questions which resulted in a lack of understanding and a sense of disempowerment. The group were really clear that they wanted to be involved in decisions about their health – crucially this demands openness and accessibility. The group talked about experiences where they felt they were **not provided with enough information** and limited explanation of their illness which left them feeling disempowered. Overall, poor communication, lack of information and the inability to understand information were barriers to having positive experiences of health and healthcare.

Our final question asked **what the group thought the priority should be for accessing good health care?**

The group highlighted four areas that they felt were a priority in general:

**Access to good quality support** is required particularly at a time when there are cut backs. The group expressed concerns that cuts in services would have a direct impact on individuals with learning disabilities and their carers. A lot of service users are also caring for their ageing parents and this must be acknowledged and the appropriate support provided.

**Accessible information** should be widely available.

**Being involved** at all stages to ensure a clear understanding of what is happening. The group said that it is essential that people with learning disabilities are active participants in their own health at all stages – even when this means planning for difficult times such as palliative care.

The group also suggested that **health professionals should be alerted to patients who have a learning disability** by means of a 'red flag' system in order that additional arrangements/supports can be put in place.



## Book Review:

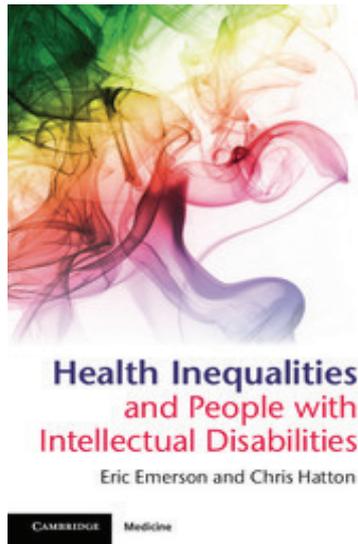
*Health Inequalities and People with Intellectual Disabilities (2014)*  
by Eric Emerson and Chris Hatton, Cambridge University Press

Lisa O'Leary  
University of Glasgow

The aim of this book is to understand the health needs of people with learning disabilities from a public health perspective. The authors argue that social determinants of health such as access to health care, housing, networks, living working conditions etc. need to be addressed in order to improve the health of people with learning disabilities. This book would be a valuable resource for policy makers, service providers, carers etc, as information is provided in relation to strategies for targeting health inequalities for people with learning disabilities. The following key messages could inform policy and practice for targeting health inequalities amongst people with learning disabilities.

### Need to build a person's capacity to promote their health

A core message of this book is that people with learning disabilities need a lot of support to meet their health needs.



Chapter 1 provides an overview of the main approaches for understanding health, health inequalities and disability. The description of the capabilities framework is useful for informing policy and practice, in order to promote health equalities for people with learning disabilities. The authors apply this framework to all aspects of an individual's life such as physical health, psychological well-being and healthcare access.

In building a person's capacity to promote their health, the focus is diverted from an individual's impairment or disability to the challenges in their environment. For example, a person with a physical disability may not have the choice to take part in an activity, due to lack of accessible facilities. The authors indicate how a supportive environment needs to be cultivated in order to enable this population to have the opportunity to build the knowledge, skills and confidence to promote their health.

This capacity-building model could inform the implementation of a weight management or physical activity intervention for people with learning disabilities. For example, investments could be made in training and developing the role of paid/family carers, so that they have the resources to support people with learning disabilities to acquire the knowledge, confidence and skills to make healthy choices.

### Need for multi-layered approach to promote health equalities for people with learning disabilities

Chapter 4 and 5 discuss how a multi-layered approach is required to target health inequalities experienced by people with learning disabilities. The authors discuss how this requires addressing individual behaviours and social context. It is important to consider the influence of the wider social context, as this population are often reliant on external supports to build their capacity to engage in and maintain healthy lifestyles.

In referring to the influence of the wider social context on health, the authors give examples of how people with learning disabilities experience discriminatory attitudes, institutional discrimination, and social exclusion etc. They highlight the implications of institutional discrimination in referring to the prominent Mencap report entitled 'Death by Indifference.' They identify how a lack of understanding and respect towards people with learning disabilities and their families can lead to a lack of effective design of policies and procedures to meet the needs of people with learning disabilities.

### Need for public health interventions

The authors make clear recommendations for how to reduce health inequalities for people with learning disabilities. They argue that interventions focussed on changing behaviours such as dietary habits are not sustainable on an individual level, and that changes need to be made initially within an environmental context. This is important so that people with learning disabilities have the incentive and resources to sustain healthy behaviours. For example they recommended the following public health interventions:

- (a) Changing environments in order to increase the likelihood of people engaging in exercise.
- (b) Policies to raise the price of unhealthy foods.

Hence, this book emphasises that policy makers should strive to cultivate a physical environment where people with learning disabilities will have the opportunity to be persuaded to make healthy choices. This could help practitioners to implement sustainable health promotion interventions.

Overall, this is a very interesting and enlightening book which makes some clear and concrete policy, research and practice recommendations for addressing health inequalities amongst people with learning disabilities.

## Who's Who?

*Linda Allan*

Honorary Clinical Associate Professor / Professional Advisor | Directorate of Population Health Improvement, Care, Support & Rights Division

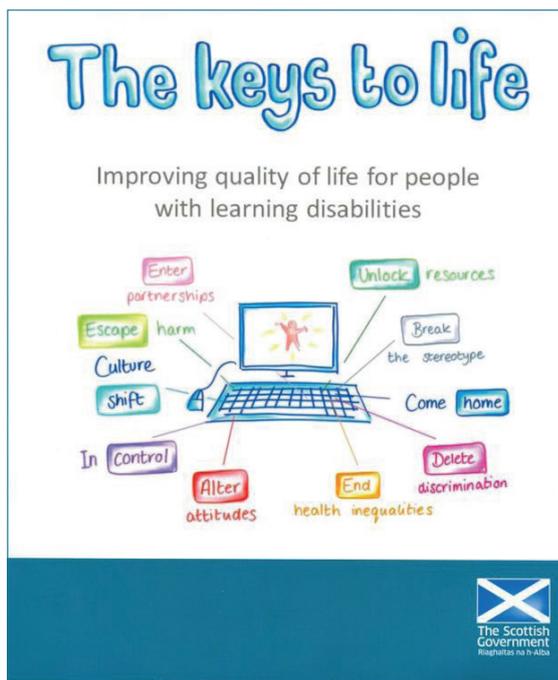
The Scottish Government

### Describe yourself in three words

Conscientious; considerate and knowledgeable.

### Could you tell us a bit about your role?

I am the professional advisor to the policy team at the Scottish Government. I advise, develop and implement National Learning Disability strategy across Scotland. This involves working with strategic and delivery partners, policy colleagues within the Scottish Government and of course individuals with Learning Disability/carers. I retain one day per week within NHS Greater Glasgow & Clyde as the Nurse Consultant for learning disabilities.



### How did you get into this area of work?

My role as Nurse Consultant involved 4 aspects – service development; research; expert practice and policy advice. I previously worked with the Scottish Government as an external advisor on the evaluation of The Same As You? This led to the development of my current role.

### Why did you want to work in this area?

Potential to influence and positively impact on the lives of people with learning disabilities.

### What is the most rewarding aspect of your career so far?

Health screening programme in NHS Greater Glasgow & Clyde which led to health gain; added to the literature and began to change GP culture. Being awarded an Honorary Professorship at the University of Glasgow.

### What is the best advice given to you in your career?

When you hit a brick wall, turn left or right and keep going. Another was to 'stop seeing everything as a great opportunity' – as often this is what I do and end up drowning in work!!!

### What one thing do you think has the potential to make the biggest difference to the health of people with learning disabilities?

Visibility in data and targeted health approaches to meet unique comorbidity.



## Cutting Edge

### *A Closer Look at Health Inequalities Experienced by Adults with Learning Disabilities*

Laura A. Hughes-McCormack

People with learning disabilities face barriers in accessing healthcare services. This is despite legal requirements for public bodies to make their services accessible, enshrined in the Equality Act (2010). The Scottish Government is making strides to tackle health inequalities experienced by people with learning disabilities in Scotland, but this is not without its challenges. The new Scottish Learning Disabilities Observatory is starting to generate evidence to help.

#### **A study on long-term conditions**

We investigated the long term conditions that 728 adults with learning disabilities have, and the primary health care they received. This was based on what general practice considers to be best practice. We compared their health care with that for other people.



#### **What we found**

The adults with learning disabilities experienced more long-term conditions than the general population. For example, they had more:

- Epilepsy (28.4% vs 0.8%)
- Serious mental ill-health (psychosis) (7.7% vs 0.9%)
- Diabetes (6.1% vs 3.4%)
- Hypothyroidism (5.0% vs 2.8%)
- Asthma (9.3% vs 5.3%)

They did not receive as much best practice for their long-term conditions compared to other people. This was the finding for all types of long term conditions.

#### **What next?**

Primary care practitioners want the best for their patients. So we will find out why there are these differences in health care. Then we will know how practices need to be differently organised or what additional supports they need to better support their patients with learning disabilities and long-term conditions.

### *Co-existing conditions*

Sally-Ann Cooper

When people have more than one health condition, it usually means their health care needs a different management approach to that for a single condition. It can also change which drug treatments can be used. There is increasing awareness of its clinical importance. Guidelines are being developed to help practitioners.

#### **A study on co-existing conditions**

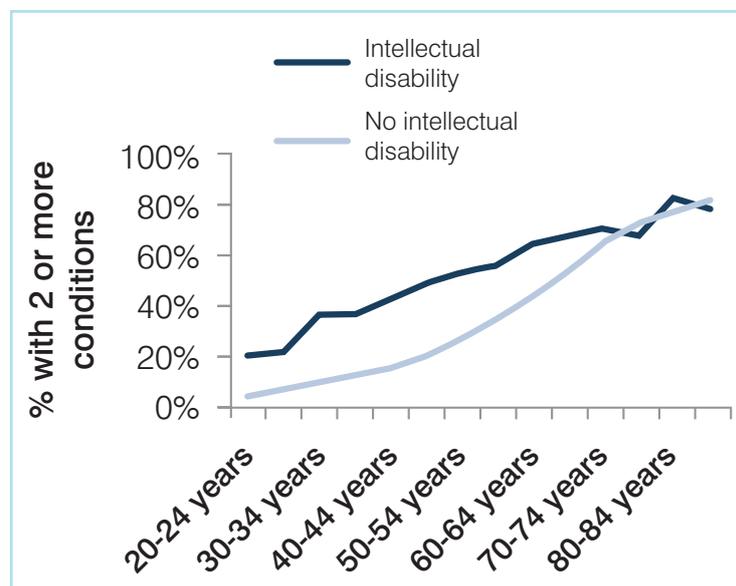
We analysed primary health-care data on 1,424,378 adults from 314 Scottish practices, 8,014 of whom had learning disabilities. We included 32 physical, and 6 mental health conditions. We compared rates and numbers of conditions for adults with learning disabilities, with other people of the same age and gender.

#### **What we found**

Only 31.8% of the people with learning disabilities had no conditions compared to 51.6% without learning disabilities. They were much more likely to have co-existing conditions, such as epilepsy, constipation, visual impairment, hearing loss, dyspepsia, schizophrenia/bipolar disorder, anxiety, and dementia. Their co-morbidity increased with age but is highly prevalent at all ages, being similar at age 20-25 to 50-54 year olds in the general population.

#### **What next?**

Policy initiatives or guidelines on co-existing conditions need to be relevant at a much earlier age for people with learning disabilities. We will spread this message widely.



## Events of Interest

The Scottish Government -  
The Keys to Life Calendar of Events 2015.

# The keys to life

Web link: [keystolife.info](http://keystolife.info)

Learning Disability Awareness Week:  
15th – 21st June 2015.



Web link: [www.sclد.org.uk](http://www.sclد.org.uk)

Cornerstone is hosting an  
Alternative Games fun day  
for the people they support on  
Wednesday 22nd July!  
Time: 11am -3pm **Venue:** East  
End Healthy Living Centre  
183 Crownpoint Road, Glasgow  
G40 2AL



There will be a huge variety of activities on offer. The event is free but places are limited. To reserve your free spot or sign-up as a volunteer on the day, please call Sharon Irvine on 0141 551 8954.

European Sociological Association Conference  
(Disability Research Stream) August 2015, Prague



EACD –European Academy of Childhood Disability  
2016 'Annual Conference on Cerebral Palsy and other  
Childhood-onset Disabilities' Stockholm 1-4th June 2015



UCL Combating Negative Attitudes & Discrimination  
against people with Intellectual Disabilities around the  
globe' 16th July 2015, London



Global Action to Combat Negative Attitudes to  
Intellectual Disability: A Free Public Event  
This project is led by researchers at University College London (UCL) and has gathered evidence from experts and  
disability organisations around the world to establish what actions are taken to achieve human rights for people with  
learning intellectual disabilities. From a small start, we have now added to gathering such information from around 700  
experts and representatives of disability organisations in 30 countries and have agreed to present our findings to the  
United Nations in New York.

The 2015 Down Syndrome Research Forum will be held  
at University College London (UCL)  
on 22 and 23 September.

down syndrome  
education international  
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The Farr Institute Conference,  
St Andrews from 26/08/15 - 28/08/15



Web link: [www.farrinstitute.org/events/](http://www.farrinstitute.org/events/)

