



Scottish

Learning Disabilities

Observatory

In this issue:

Scotland's 2011 Census Studies

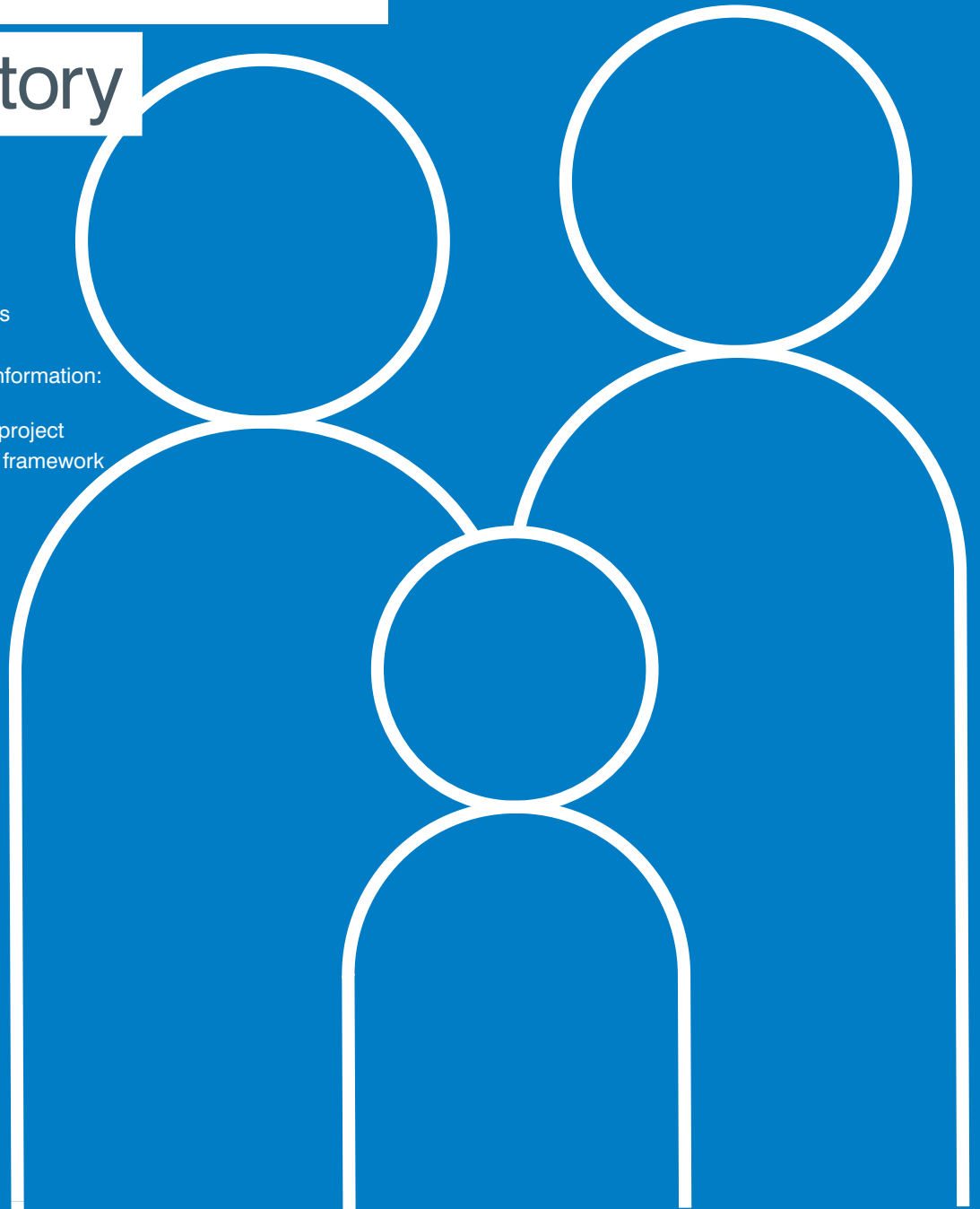
Observatory Updates

The Importance of accessible information:
an independent view

The learning disabilities SPIRE project

The keys to life implementation framework

SLDO conference programme



**Scottish Learning Disabilities Observatory
Newsletter Volume 2, November 2015**

Scottish

Learning Disabilities

Observatory



November 2015

Newsletter Welcome

In this edition of the Observatory newsletter, we are highlighting our first conference. We organised the conference so that members of the public with and without learning disabilities, practitioners, service commissioners and managers, and policy makers, can get to know the work we are progressing. We are keen to consult on which Observatory work areas you think are important in order to understand and improve health inequalities for people with learning disabilities. After the conference, we want to know if it was useful, and if so, how we can improve its format for future events. I am very grateful to the people supporting the Observatory by contributing to the conference; Professor Chris Hatton will be sharing the English experience, and Professor Mike Kerr will be sharing approaches from Wales, to complement the work we will be presenting from Scotland. We are grateful also to Mr James Hepburn, MSP, and Dr Maureen Bruce from the policy team at the Scottish Government for showing the work of the Observatory within the context of Scottish priorities, and The Keys To Life implementation framework, ensuring our direction is firmly grounded in moving forward Scottish policy to benefit people with learning disabilities. The Good Life Group will remind us all exactly why we are doing this work, and I am very pleased they agreed to contribute to the conference. The afternoon sessions will include discussions informed by presentations by Mr Lyall Cameron and Dr Helen Lynn (NHS Ayrshire and Arran); Dr Mandy Allison and Ms Stella Morris (NHS Lothian), and Ms Catherine Thomson (Public Health Intelligence), giving a broad range of actions across Scotland. Professor Sir Ken Calman, and Mr Chris Creegan will kindly be keeping the conference on track by chairing the sessions.



We are also excited to be presenting information about the population with learning disabilities from Scotland's Census, 2011. This is a rich source of information about everyone with learning disabilities in Scotland. I would particularly like to thank Venetia Haynes, Cecilia MacIntyre, and Mrs Julie Rintoul, from National Records of Scotland and Analytical Services Division, who have been instrumental in the development of this exciting work.

I hope you enjoy the conference and this newsletter. If you can't make the conference on the 1st of December, check out our website on www.SLDO.ac.uk for more information! We are currently adding information to our website every week, so have another look!

Professor Sally-Ann (“Anna”) Cooper
Director of the Scottish Learning Disabilities Observatory

Scotland's 2011 Census Studies

Health of people with learning disabilities in Scotland - a total population study

Laura Anne Hughes-McCormack

Why is this project important?



Scotland's Census is the official estimate of people and households in Scotland. The information about the Scottish population is collected every 10 years. For the first time in 2011, the Census questionnaire also included a question on learning disabilities. At the level of the whole population, little is known about the characteristics and health status of people with learning disabilities living in Scotland.

Census Study

We analysed Scotland's Census 2011 data for people with learning disabilities, and compared it to the information on the whole population. We investigated age, gender, place of birth, ethnicity, languages spoken, employment and self-rated health.

What we found

26,349 (0.5%) of people were reported to have learning disabilities. Unlike the whole population, more males (n=15,149; 57.5%) than females (n=11,200; 42.5%)

have learning disabilities. A lower proportion of people with learning disabilities reported their health as very good or good (50.2%), compared to 82.2% of the general population. Most people with learning disabilities (97.2%) were born in the UK, similar to the whole population (93.0%). They were also mostly white (97.3%) compared with 96.1% of the whole population. The majority lived in a home where English was spoken (90.29%), compared with 92.6% of the whole population. British Sign Language (2.6% versus 0.2% for the whole population) and Scots (1.0% versus 1.1% for the whole population) were the other two most common languages spoken by people with learning disabilities.



How might this study benefit people with learning disabilities?

This project will add to the existing body of knowledge on health inequalities faced by people with learning disabilities. Patterns of vulnerabilities or inequalities identified for people with learning disabilities will help inform health and social care policy and practice. This work is still in progress; subsequent analyses will explore the extent to which individual and household characteristics impact on health of people with learning disabilities.

If you would like more information, you can contact Laura at Laura.Hughes-McCormack@glasgow.ac.uk.

Health of People with Autism in Scotland. A whole country cohort study.

Dr Ewelina Rydzewska

Why is this project important?



Autism is common. However, little is known about demographic factors and health status of people with autism in whole country populations. For this reason, we are analysing Scotland's Census 2011 data, and generating information about people with and without autism. Amongst other factors, we are investigating health, age, sex, place of birth, ethnicity, and languages spoken.

What have we found so far?

Very good or good health was described for 72.0% of people with autism, compared to 82.2% of all people. Most people with autism (96.8%) were born in the UK, similar to the whole population (93.0%). They were also mostly white (97.0%), similar to the whole population (96.1%). The majority lived in a home where English was spoken (92.4%), compared with 92.6% of the whole population. British Sign Language (1.5% versus 0.2% for the whole population) and Scots (1.2% versus 1.1% for the whole population) were the other two most common languages spoken by people with autism.

People with autism (n=31,712) comprised 0.6% of the total population of Scotland (n=5,295,403). There were more males (n=24,490; 77.2%) than females (n=7,222; 22.8%) with autism. The prevalence of autism was 0.8% for girls and 3.0%

for boys in the 0-15 year group; 0.5% for girls and 1.9% for boys in the 16-24 year group; and then progressively fell with each subsequent older age group, reflecting the considerable increased awareness and improvement in availability of diagnostic services for autism over the last two decades.

How might this project benefit people with autism?

This project will add knowledge on the health inequalities of Scotland's population with autism. If patterns of vulnerabilities or inequalities are identified, they can be used to inform service delivery for people with autism in a more evidence-based way. Our work with the Census information is still in progress, and we intend to investigate whether and how individual and household characteristics impact on health of the population with autism.

Where did this information come from?

This section presents findings from analysis of Scotland's Census 2011 data. If you have an enquiry that specifically relates to Scotland's Census 2011, please contact National Records of Scotland (NRS) Customer Services at customer@gro-scotland.gsi.gov.uk or visit www.scotlandcensus.gov.uk.

If you would like more information, you can contact Ewelina at ewelina.rydzewska@glasgow.ac.uk.



Observatory Updates

The prevalence of physical ill-health in a cohort of adults with learning disabilities in Scotland.

Dr Deborah Kinnear

Why is this project important?



People with learning disabilities have different health needs and experience greater health inequalities when compared to the general population. Gastro-oesophageal reflux disorder, sensory impairments, osteoporosis, dental disease, musculoskeletal problems,

accidents, and nutritional problems are all thought to be much more commonly experienced in people with learning disabilities. However, most studies have been small scale, with selected age groups, or methodologically limited. We therefore need to better understand the physical health of people with learning disabilities.

This project is important as it identifies the physical health conditions experienced by people with learning disabilities using a robust study design in a large population. The adult population (aged 16 years and over) of people with learning disabilities living within the geographical area of Greater Glasgow Health Board, Scotland, were identified and recruited to the cohort study. Each participant underwent a comprehensive health assessment by nurses and three general practitioners. This research aims to identify the most prevalent physical health conditions experienced by people with learning disabilities.

How may the project benefit people with learning disabilities?

The Keys to Life highlights that people with learning disabilities have some of the poorest health of any group in Scotland. This project will help us to identify, and therefore highlight to practitioners and support workers, the most prevalent physical health conditions of people with learning disabilities. In doing so, we will provide evidence to inform training developments.



If you would like more information, you can contact Deborah at Deborah.Kinnear@glasgow.ac.uk

Impact of hate crime and targeted violence on the health and wellbeing of people with learning disabilities in Scotland

Dr Phillippa Wiseman

Why is this research important?



People with learning disabilities are thought to be between two and four times more likely to experience hate crime, targeted violence and harassment more often than other disabled people and the general population.

Disability hate crime has been a burgeoning area of research, however there has been very little exploration into learning disability as a distinct population with distinct experiences of harassment and violence. Moreover there has been even less examination of the impact that targeted violence and bullying might have on people's lives, health and wellbeing. It is known, generally, that people who have been subject to hate crime or violence experience poorer physical, emotional and mental health. Therefore it's important that research takes place in collaboration with people with learning disabilities to find out how their health might be affected by hate crime and violence.

Qualitative research that is inclusive of people with learning disabilities will help us understand more about the social determinants of their health and wellbeing.

How will this research benefit policy and practice?

The Keys to Life has specifically pinpointed hate crime and targeted violence as key issues affecting the lives of people with learning disabilities. Gaining insight into people with learning disabilities' everyday experiences and the impact of hate crime and violence will help us better understand how to improve prevention, reporting and support services as well as reduce health inequalities for people with learning disabilities. Focusing on how hate crime impacts health and wellbeing will generate data that informs an area of people with learning disabilities' lives that have received too little attention.



If you would like more information, you can contact Phillippa at Phillippa.Wiseman@glasgow.ac.uk

Comorbid Health Conditions in People with Autism

Dr Ewelina Rydzewska

Why is this project important?



People with autism experience a wide range of health problems, some of which may be more common than it is the case for all people. Existing research includes studies on the co-occurrence of neurological, gastrointestinal, metabolic, autoimmune, mental and genetic disorders. Some of these conditions seem to occur within families. Others, such as epilepsy, are more common in people with autism and learning disabilities. Many of the health problems co-occurring with autism lead to emotional distress, physical discomfort, and reduced quality of life.

Reviewing relevant systematic reviews of studies and meta-analyses of evidence on co-morbidity in autism will help us investigate the prevalence of co-occurring health needs of people on the spectrum, identify gaps in existing research and make recommendations for future studies.

How might this project benefit people with autism?

Addressing the gap in research on health problems experienced by people with autism can help inform development of guidelines and training for improved detection and intervention. Such practice and policy developments are ultimately aimed at improving quality of life for people with autism and are closely aligned to values placed at the core of the Keys to Life and Scottish Strategy for Autism recommendations.



If you would like more information, you can contact Ewelina at ewelina.rydzewska@glasgow.ac.uk.

A systematic review of hospital admissions for people with intellectual disabilities

Kirsty Dunn

Why is this project important?



People with intellectual disabilities may be admitted to hospital more frequently, and for different reasons than the general population. Within the Canadian health care system, there is a suggestion that people with ambulatory care conditions (like diabetes and asthma)

may be more likely to be admitted to hospital if they have learning disabilities. Ambulatory care-sensitive conditions are defined as conditions which, if managed effectively at the primary care level, should not lead to a hospital admission. We are undertaking a systematic review on this topic. It is important as it will investigate the reasons that people with learning disabilities are admitted to hospital, whether they are admitted for ambulatory conditions more often than the general population, and identify research gaps in this area.



How might this project benefit people?

We need to understand why people with learning disabilities are admitted to hospital, and if this occurs at the same rate as for other people with the same health care conditions. If people with learning disabilities are admitted more often, then focussed effort will be required to address the reasons for this. This is particularly so in the case of ambulatory conditions, as it would be suggestive of underlying poor healthcare or support.

If you would like more information, you can contact Kirsty contact Kirsty at Kirsty.wright@gla.ac.uk

Management of long term health conditions amongst adults with learning disabilities in primary care settings

Laura Anne Hughes-McCormack

Why is this project important?



People with learning disabilities experience poorer health and higher levels of multi-morbidity in comparison to the general population. To help reduce inequities, primary health care providers need to effectively manage long-term conditions in keeping with best practice.

We want to find out how long-term conditions are managed within primary health care for adults with learning disabilities, compared with the general population. We also want to find out the number of recognised health conditions experienced by adults with learning disabilities compared with the general population, and the potential influence of a range of individual, social and environmental factors upon these health problems.

How might this benefit people with learning disabilities?

General practitioners and practice nurses wish to provide the best care for all of their patients, including adults with learning disabilities. This study should be important in raising awareness, and focussing attention on this group, given their high prevalence rates of long-term conditions. General practices are facing challenges in providing the best quality care for their patients with learning disabilities, and we need to find practical and implementable means to support practices in achieving this via a “whole systems” approach.



If you would like more information, you can contact laura at Laura.Hughes-Mccormack@glasgow.ac.uk

PhD project: The effect of transition on health and wellbeing in young people with learning disabilities.

Genevieve Young-Southward

Why is this research important?



Transition refers to moving from childhood to adulthood; developing adult roles and achieving increased independence from parents or caregivers. Lots of changes occur during this time, for example leaving school, moving from child to adult services, and adjusting to adult roles and expectations. These changes may be stressful or difficult to cope with, which, combined with the change in support that may occur for young people with learning disabilities at this time, may make this a difficult period for young people.

Evidence suggests that people with learning disabilities have poorer health than those without disabilities in general, and transition may be a period when health and wellbeing may be particularly at risk. This research aims to look at whether transition affects health and wellbeing in young people with learning disabilities, and in what particular ways. This will be achieved through interviews with young people currently experiencing transition and their families, as well as secondary analysis of data that has already been collected. Transition is a vital period in a person's life, and as all young people will experience transition in some form, it is vital that we understand the impact that it has on health and wellbeing, in order to support young people in the future.



How will this research benefit policy or practice?

This research will provide us with a better understanding of the ways in which health and wellbeing is affected during the transition period. Importantly, this research will be very much informed by the voices of young people with learning disabilities themselves, in order to accurately portray their own experiences. If we fully understand the ways in which transition impacts health and wellbeing in young people with learning disabilities, we can work towards developing supports and services that promote a healthy and happy transition for young people in the future.

If you would like more information, you can contact Genevieve at g.young-southward.1@research.gla.ac.uk

Causes of death and life expectancy of people with intellectual disabilities: a systematic review

Dr Lisa O'Leary

Why is this project important?



People with learning disabilities are at risk of experiencing poorer and possibly avoidable health outcomes in comparison to the general population. This may lead to premature death and lower life expectancy for individuals with learning disabilities.

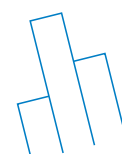
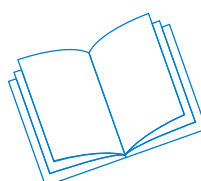
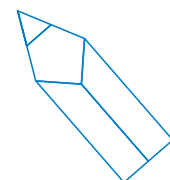
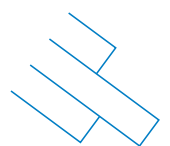
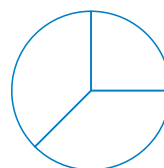
We are conducting a systematic review in order to identify the main causes of death and life expectancy of this population group. This will throw light onto how we can intervene to reduce avoidable deaths.



How might this project benefit people?

Findings from this review will address recommendations in the 'Keys to Life' document. These findings will hopefully help develop a better understanding of the causes of unnecessary deaths of people with learning disabilities. This understanding will potentially inform improvements in practice, and generate strategies to reduce unnecessary deaths in the future.

If you would like more information, you can contact Lisa at Lisa.O'Leary@glasgow.ac.uk



'The importance of accessible information: an independent view'

Michael McEwan, Freelance Journalist and Presenter

Why do we need a Scottish Learning Disabilities Observatory?



Information about the health of people with learning disabilities is really important. It is important that doctors, nurses and other professionals, who support people with learning disabilities, have access to good quality information.

I am really pleased that the Scottish Government is funding this new centre. I hope that they continue in years to come and the Centre will carry out some good work.

What I would ask for is that the research that is done by the new Learning Disabilities Observatory is made accessible to people with learning disabilities.

For people with learning disabilities, access to better information about their health is really important. We want to be included in decisions about our health and care. And to make decisions we need to have information that can support us to make the right choices about our own lives. We need better information.

But what do we mean by better information?

For me this is about 2 things – it is about the right information and it's about accessible information.

I want to know that the information that my doctor or nurse uses in their day to day practice is based on good quality evidence. That's where there is a real need for this observatory in Scotland.

But it is also really important that I also have access to the same information. I am not a professional so I will need information that doesn't include lots of technical words or jargon. Clear accessible information is important for everyone – not just people with learning disabilities.

What has helped me, and a lot of people with a learning disability, is Easy Read information.

Easy Read information is presented with descriptive images which make it clearer and easier to understand.

For organisations who want to support people with learning disabilities to better understand written information I would ask them to develop easy read resources. After all how can people with learning disabilities really be supported to make informed decisions about their own health and care without access to good quality information in ways that can be easily understood?

So for me a really important part of the journey towards better health for people with learning disabilities is better information.

It's not just about how things are written. For doctors and other professionals this means using accessible language when they are talking to people with learning disabilities about their care and support. It means talking to the individual they are supporting in a supportive and clear way. Again no jargon please!

There are lots of examples of good information being developed for people with learning disabilities.

I know when I have been to different disability organisations for meetings they will make sure that the information being presented or talked about is accessible to everyone in the room. I would like to see more mainstream organisations do the same.

There are a lot of good websites out there written in Easy Read, like the Keys To Life site and NHS EasyInfo Zone.

The Keys to life, learning disability strategy, really leads the way in telling us why it important to focus on health. It also says that people with learning disabilities need to have a say in how these new policies develop. This is a good starting point, to give a voice and control back to people with learning disabilities, a say in how services can be improved. For years we have been told what to do, rather than being equal participants in these developments.

Better information in accessible formats is an important step towards this.

I look forward to hearing what new work they do and I wish them luck.

Learning disabilities SPIRE project

Angela Henderson, Deputy Director of the Scottish Learning Disabilities Observatory



The core mission of the Scottish Learning Disabilities Observatory is to help build the evidence that can contribute to addressing the considerable health inequalities experienced by people with learning disabilities.

Better information about the health of people with learning disabilities is crucial to achieving this mission. Routinely collected health information provides a rich source of data about the health of the general population and Scottish health systems have developed a robust infrastructure for delivering high quality data and population level health intelligence.

The Scottish Government is leading the way with an ambitious programme of work designed to increase the utilisation of administrative data from health and social care systems to help build a better understanding of the health and wellbeing of the whole population. The Scottish Primary Care Information Resource, SPIRE, is an important strand of work that aims to improve the collection and analysis of information from GP systems. Through extraction of information that is currently held locally within individual practices, SPIRE will be able to provide anonymous information that can streamline practice level reporting across a wide range of health indicators, as well as supporting service audit, monitoring health trends, and research at a national, regional or local level.

Clearly patient confidentiality and choice is a central consideration of the SPIRE system and a robust information governance framework is in place to ensure that patient information is safeguarded.

The information held by GPs about the population has the potential to help build our understanding of the health and health inequalities experienced by people with learning disabilities, a key goal for national learning disabilities policy in Scotland. An example might be by providing comprehensive Scottish-level information about the management of a wide range of conditions and comparing whether this is as good as for the general population.

To help support the programme of work in relation to learning disabilities data, the Scottish Learning Disabilities Observatory is working closely with partners from across the NHS, General practice and the Scottish Government. The SPIRE learning disabilities data project aims to develop a work stream specifically on people with learning disabilities to enhance our understanding of their health and healthcare across Scotland.

If you would like more information about the SPIRE project you can visit the website at www.spire.scot.nhs.uk or if you would like more information about the SPIRE learning disabilities data project please get in touch with Angela Henderson at the Scottish Learning Disabilities Observatory (angela.henderson@glasgow.ac.uk)

The keys to life implementation framework

Angela Henderson
Deputy Director,
Scottish Learning Disabilities Observatory

Linda Allan
Honorary Clinical Associate Professor /
Professional Advisor | Directorate of Population
Health Improvement, Care, Support & Rights
Division,
The Scottish Government



Angela Henderson



Linda Allan

At the launch of 'The keys to life' in 2013 the Minister for Public Health said that addressing the poor health of people with learning disabilities was a major priority for Scottish Government policy. He said that this was, at its heart, about human rights and the mission to make the rights of people with learning disabilities a reality.

Two years on the Scottish Government has reasserted the centrality of human rights to achieving the goals of learning disability policy in Scotland with the publication of 'The Keys to life Implementation Framework'.

This new framework outlines a refreshed delivery approach which reflects the voices of people with learning disabilities in Scotland, the cornerstones of the Scottish Programme for Government and the 52 recommendations of the strategy. Priorities and actions for the next 2 years have been explicitly aligned to the UN Convention on the Rights of People with Disabilities. This Convention provides a route map for public authorities to enable them to take decisive action towards making human rights a reality for disabled people.

Four strategic outcomes have been set by the Scottish Government:

A healthy Life: People with learning disabilities enjoy the highest attainable standard of living, health and family life.

Choice and Control: People with learning disabilities are treated with dignity and respect, and protected from neglect, exploitation and abuse.

Independence: People with learning disabilities are able to live independently in the community with equal access to all aspects of society.

Active citizenship: People with learning disabilities are able to participate in all aspects of community and society.

The refreshed delivery approach to learning disabilities policy implementation outlines a greater emphasis on cross policy partnership working. Ensuring the inclusion of people with learning disabilities across all policy areas is a key theme within the approach.

As a strategic partner of the Scottish Government the Scottish Learning Disabilities Observatory has a key role in delivering this vision of sustainable change, mainly through our contribution to increasing the visibility of people with learning disabilities in routinely collected health and social care data. By focusing on this the Scottish Government is acknowledging the critical role that good quality information can play in reducing the health inequalities of people with learning disabilities.

The new implementation plan also emphasises the need to align the delivery of these priorities and objectives across strategic partner and delivery organisations. Engagement with our diverse audiences will also support achievement of this goal. The development of an effective approach to inclusion is crucial to delivering a human rights based approach in any area of public health policy. For the Scottish Learning Disabilities Observatory this means making sure that the voices of people with learning disabilities are at the centre of our work programme.

It is welcome that the Scottish Government are actively promoting a human rights based approach to implementation of learning disabilities policy. You can download a copy of the new implementation plan at The keys to life website. www.keystolife.info

Better information, better health

1st of December 2015

COSLA Conference Centre, Verity House, Edinburgh EH12 5BH

PROGRAMME

9.30 - 10.20	Registration
10.20 - 10.30	<i>Welcome and introduction from the Chair</i> Professor Sir Ken Calman, Chancellor of Glasgow University
10.30 - 11.00	<i>Health surveillance and people with learning disabilities: the English experience</i> Professor Chris Hatton, Professor of Psychology, Health and Social Care
11.00 - 11.15	Mr Jamie Hepburn, Minister for Sport, Health Improvement & Mental Health
11.15 - 11.45	Tea and coffee break
11.45 - 12.15	<i>Reducing health inequality in people with intellectual disabilities in Wales: it's all about the data</i> Professor Mike Kerr, Clinical Professor
12.15 - 12.45	<i>The Good Life Group</i> Ms Angela Halpin, Ms Dawn Baxter, Mr Brian Robertson, Ms Sally Swadel and Ms Linda McLaughlin
12.45 - 1.50	Lunch
1.50 - 2.00	<i>Welcome back from the Chair</i> Mr Chris Creegan, Chief Executive, Scottish Consortium for Learning Disability
2.00 - 2.30	<i>The Scottish Learning Disabilities Observatory – now and beyond</i> Professor Anna Cooper, Director of the Scottish Learning Disabilities Observatory
2.30 - 3.15	<i>Primary care data: a growing national picture</i> 1. Ms Stella Morris and Dr Mandy Allison, NHS Lothian 2. Mr Lyall Cameron and Dr Helen Lynn, NHS Ayrshire & Arran 3. Ms Angela Henderson and Ms Catherine Thomson, SPIRE
3.15 - 3.45	<i>Discussion groups</i> Facilitators: Ms Rona Laskowski, NHS Lothian, Mr Peter McCulloch, Renfrewshire Council, Professor Anna Cooper and Ms Angela Henderson, Scottish Learning Disabilities Observatory and Fiona Wallace, People First
3.50 - 4.00	<i>Feedback from discussion groups</i> Mr Chris Creegan
4.00 – 4.15	<i>Closing comments from the Scottish Government policy team</i> Dr Maureen Bruce, Deputy Director & Professor Linda Allan, Professional Advisor, Care, Support & Rights, Population Health Improvement Directorate

Scottish Learning Disabilities Observatory,

Mental Health and Wellbeing, University of Glasgow, 1st Floor, Admin Building,
Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH
Email: sldo-info@glasgow.ac.uk Telephone: 0141 211 0688